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ABSTRACT

This document contains 16 papers that were scheduled to be presented at a conference (which was canceled) on approaches and programs for helping developmentally disabled persons to be more self-sufficient. The book is divided into three sections: (1) unmasking vocational abilities, (2) enhancing functional independence, and (3) medical and communication intervention. The following papers are included: "Marc Gold's Training in Industrial Work Sites as a Placement Approach" by Marianne Roche; "The Pay-off's a Paycheck: Employment Preparation for People with Severe Disabilities" by Ronald S. Torner; "Jobs for People with Epilepsy" by Robert A. Anderson; "A Competitive Industry of Severely Disabled Workers" by John H. Leslie, Jr.; "Redesigning Sheltered Work Environments" by Jay Belding; "Needed: Creative Vocational Evaluations" by Elaine M. Shaver; "Specialized Seating Mobility--Technical Considerations" by Douglas A. Hobson; "Systems for Independent Mobility" by E'Lise B. Brown; "Concealable Helmet for Seizure-Prone Individuals" by James L. Mueller; "Support and Rehabilitation Services for Severely Orthopedically Disabled College Students" by Rodger W. Decker; "Small Steps on an Unpaved Path (Malcontents Biting the Hand that Feeds)" by Derrick Dufresne; "Mouthguard for Drooling Control" by Jacob Harris; "Protective Aids" by Wu S. Chiu; "Anticonvulsant Abuse in Institutions" by Anis Racy; "Communication Aids and Systems Clinic" by Donna DePape, and "Biofeedback for Head Control" by Carol Leiper. (KC)

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UNMASKING ABILITIES

HIDDEN BY DEVELOPMENTAL CONDITIONS

Edited by

Kalisankar Mallik and Elaine M. Shaver

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PREFACE

The Job Development Laboratory of the Division of Rehabilitation Medicine, The George Washington University, Washington, D.C., was involved in a three-year project (October 1976 to September 1979) entitled "Technical Support Services to the Developmentally Disabled in Region III." Funded by the Region III Developmental Disabilities Office, Office of Human Development, U. S. Department of Health, Education and Welfare, Philadelphia, Pennsylvania, the overall purpose of the project was to improve the quality of life for Region III persons who are developmentally disabled, specifically the mentally retarded, cerebral palsied, and epileptic.

The project staff adopted a problem/solution approach. Through the project period the staff sought to identify the most common problems faced by Region III facilities serving the developmentally disabled in the medical, life skills, prevocational, and vocational areas. Technical solutions were then sought for each identified problem. The staff focused heavily on disseminating the solutions obtained through such efforts, and produced several books, newsletters, pamphlets, and a videotape. The staff also conducted numerous training workshops and seminars in which project findings were shared regionally and nationally.

During the three years of the project, the staff came across a number of innovative and commendable efforts to assist developmentally disabled persons to be self-sufficient. These efforts were varied, ranging from fundamental concerns such as communication to more specific concerns such as driver training. Because these "discovered" programs and approaches were so unique and effective, it seemed desirable to put representatives of each program directly in touch with concerned and interested Region III people. A conference was conceived as a culminative product of this project in which these innovative practitioners would share their expertise and experiences with conference participants.

"Unmasking Abilities in the Developmentally Disabled," a three-day national conference, was planned by the Job Development Laboratory to be held at The George Washington University from March 11-13, 1980. Unfortunately, an insufficient number of registrants forced the cancellation of the program. Nonetheless, a number of people expressed great interest in the contents of the program, and much enthusiasm was generated for publishing and distributing the information which would have been presented had the conference been held.

Because of this interest, and because the staff firmly believed in the value of disseminating information about the innovative approaches which the conference would have addressed, the decision was made to publish this collection of articles written by those who were to have spoken at the conference. This book is divided into three sections, one for each session which was to have been held during the conference: (1) Unmasking Vocational Abilities; (2) Enhancing Functional Independence; and (3) Medical and Communication Intervention.

We hope that by being exposed to these unique programs, the reader will be encouraged to attempt similar innovative approaches to solving problems faced by the developmentally disabled population in the United States.

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SECTION I

UNMASKING VOCATIONAL ABILITIES

MARC GOLD'S TRAINING IN INDUSTRIAL WORK SITES AS A PLACEMENT APPROACH

by

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In a bookstore in Center City Philadelphia, a tall, robust gentleman about 35 was overheard to say to the cashier, as he was paying for some purchases, "It really irks me about these handicapped people. They can stay home and collect all this welfare and no one expects anything out of them."

One of the most interesting beliefs that has been articulated in the last 15 years -- since the birth of Lyndon Johnson's "Great Society" -- is the assumption that every American citizen has a right to participate and contribute. The implication is that American society operates something like a "Giant Bank" where citizens invest their education, time, skills and expertise, in the anticipation that the "Bank" will pay out the dividends of a more comfortable and financially remunerative life style.

It has been only very recently that developmentally disabled citizens have been deemed qualified to be investors in this Bank. Clearly, comments such as those made by the gentleman in the bookstore, reflect a barrier to disabled people and point out that they are not, for the most part, included. Even more sinister is the bias that they should not be included in the mainstream and that their exclusion is legitimate.

Marc Gold, President of Marc Gold & Associates, Inc., and a former Research Associate Professor at The University of Illinois at Urbana-Champaign, is one of the most outspoken opponents of these separatist views. In the late 60's and 70's, Marc developed the Try Another Way technology. This system incorporates both a philosophical and technological structure.

The philosophy states that people labeled developmentally disabled can learn when taught with appropriate instructional strategies. Also, these people can learn sophisticated and complicated tasks.

The technology is an organizational structure for all of the decisions that have to be made when designing powerful training procedures. The

technology presently includes strategies for teaching a wide variety of tasks to a wide variety of people.

Assumed into this system is a premise that everyone, and more overtly the business world, operates within the rules of the "Bank." Historically, developmentally disabled people have been seen as only requiring philanthropy and benevolence (which is, as Marc would say "...a badly paved one-way street"). The technology now exists to re-orient those who have what might be called a "barrier of the mind" and encourage them to hire the competent, who also happen to have handicapping conditions, rather than the handicapped, who it is believed have few, if any, competencies.

Some of the more successful approaches that Marc Gold & Associates have used are:

1. Providing the logistics for the development of an "in-house" working committee in a particular company. The responsibility of this committee is job selection. Committee participants would include representation from administration, personnel, foremen, etc.
2. Development of a project to hire the mentally retarded sons, daughters, brothers, sisters of current employees.
3. Development of a work station. A work station is a placement and training approach whereby two to 10 developmentally disabled people are hired by a specific company and are trained together. As people reach a certain level of proficiency on the skill or skills required, they, individually, move into the usual work areas with other employers.

Currently Gold & Associates is providing training expertise to the Motorola Corp. in Austin, Texas. This partnership is known as The Austin Project. The purpose of The Austin Project is to quickly and systematically provide developmentally disabled people with new skills with which to obtain permanent, unsubsidized employment. Other benefits have included the enhancement of dignity, self-worth and quality of life to handicapped people; meeting industrial needs of this electronics company by training people for full time employment; and increasing the private sector's participation in the design and operation of employment and training programs by their involvement with Gold & Associates' training staff.

To date, 10 developmentally disabled people are in various phases of training.

Testimony to the success of this endeavor has been summed up by Edward Williams, a 22-year-old trainee in The Austin Project. When asked why he is working at Motorola, he said, "I've been living with my mother, a widow, for the past three years. She's really worked hard so that she, my brother and I could be a family. I really want this job. Now it's my turn to contribute."

THE PAY-OFF'S A PAYCHECK
(EMPLOYMENT PREPARATION FOR PEOPLE WITH SEVERE DISABILITIES)

by

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Most American adults live their lives in a world of intense productive activity. In fact, work is so commonplace that most people take it for granted.

Attitudes toward work have varied throughout the ages, and conflicting attitudes exist today. However, whether a godly gift or a curse, work is one generally accepted criterion for full adult membership in our American society.

Unfortunately, this very same society appears reluctant to allow disabled people to become adults. In the best Christian tradition, they are entitled to the protection of society but not to participation in it. They are thought of not as unemployed, but as unemployable. These are the time-honored notions. Consequently, it is not surprising that the traditional attitude in this country, when providing services for disabled adults, has been to divide them into two groups--the disabled who are "employable" and the severely disabled who are not.

The time has long passed when those of us involved in providing evaluation, training and placement services for persons with severe disabilities can perpetuate this rationalization. It only serves to mask difficulties rather than deal directly with problems that must be solved. We are either part of the problem or part of the solution.

For the people who are content with perpetuating low levels of success and low functional employment capabilities, using prediction as a means of screening individuals out of something, or who believe that we have succeeded so long as the less severely disabled persons are kept busy in workshops, this presentation has no value. For the people, however, who believe that there is a substantial gap between how persons with severe disabilities function vocationally, and how they could function, it is our position that certain changes would greatly enhance the chances for economic viability of persons with severe disabilities, and that the expertise and technology developed over the past three years will allow the achievement of this goal within the existing value structure of contemporary society.

Today, the pressures to have rights recognized are becoming ever more insistent and universal. Individuals and groups loudly insist on their right to live their own lives, to make their own decisions, to work and to earn self-respect.

In a certain sense, this freedom movement is right. In the modern era of automation, real employment for most, if not all, people with disabilities is a new option. To be deprived of this is the ultimate personal indignity. But, if this strong sense of what is owed to them is to be balanced by an equal sense of their own obligations, it may not be amiss to point out that modern champions of freedom sometimes overlook an essential step on the way to the goal they seek. The problem of employment is seen as a question of suitable accommodation, technical aids, practical arrangements, etc. They believe that employment follows automatically if only the employer would provide improved accommodations and remove certain barriers.

All of these factors are certainly of great importance. The results of our experience, however, compel us to stress the fact that the ability to work is as much a psycho-social process, as it is cognitive or motor. People who are already adult and untrained need a process of re-education and training that will, in addition to all else, enable them to learn those kinds of personal skills and behaviors and the self-constraints that will not only make them "employable," but will also assist in insuring that they are "placeable."

Placement problems, then, do not appear to stem so much from lack of available services as from lack of service integration that enables a trainee's capabilities to match a job's requirements. All too often, the individual's needs, vocational abilities or weaknesses are overlooked, or only minimally recognized. Too frequently, the name of the game is "How quickly can we get someone a job?" The result of this failure to plan ahead and establish a precise vocational goal in a systematic manner is often, for the trainee, a pattern of sheltered placement, or at best, a pattern of job failure, vocational and personal dissatisfaction, and termination of competitive employment. Indeed, the currently prevalent view of placement services presents a most serious obstacle to the improvement of vocational services, especially for people with severe disabilities.

What can we do, however, to diminish the currently embarrassingly large number of false positives, and the negatives? We can start by recognizing that the goals of the entire vocational process cannot be pre-established on a set of procedures, but must be an integral function of an individualized training program. How much more meaningful would it be to establish vocational goals that lead naturally to the process of vocational evaluation? Thus, a vocational goal to be a welder, a drill press operator, a lathe operator, a clerk-typist, a receptionist, an offset press operator or a security monitor requires specific skills. For example, security monitoring requires attending behavior, auditory discrimination skills, motor skills that allow legible entries to be logged, knowledge of the immediate locale, ability to use radio communication clearly, as well as the ability to handle periods of boredom interspersed with moments

of crucial decisionmaking in emergency situations. Once such a goal has been established, the information gathering process has a rationale.

The basic concept of situational assessment seems to provide the most fruitful approach. However, major changes in present usage must occur. The length of time and conditions necessary to learn various job tasks must be separated from the quality and quantity of performance after the tasks have been learned. The separation of these two critical areas results in more meaningful and useful data and training will necessarily occur, simultaneous with evaluation.

The complex demand characteristics of the labor market, from the biases and predilections of employers, to the constraints and social pressures imposed by co-workers, to the work-related personal habits and skills of the employee, can all be systematically included. The result is a matrix of work situations that constitute the majority of the trainee's experience and yields concrete, hard data and yet descriptive information and demonstrable changes in behavior. Such an approach also insures a more realistic relationship between evaluation and training.

Training, as the term is used in industry, usually refers to specific skills taught for specific jobs. This means bridging the gap between existing and desirable conditions. The only legitimate justification for a training program, therefore, is the reduction or elimination of a genuine difference between what someone can do and what he or someone else would like him to be able to do. Borrowing from industry, this involves job analysis, i.e., an examination of the task requirements for specific jobs, and manpower analysis, i.e., the skill, knowledge, or attitudes needed by each employee. In other words, the objective data contained in the trainee's profile is carefully compared to the employer's specifications of present job openings. The specific personal skills, work behaviors and physical capabilities are integrated into the total process of matching an individual to a given job opening and training him to fill it.

It is precisely this objective profiling of both jobs and participants that provides direction for the individualized job skill training. Training is tailored to a specific job, and it systematically teaches specialized skills. This is a particularly critical point for the more severely disabled individuals. There is little reason to train generalists, when specialists are required. For example, you do not train machinists, you train drill press operators, or lathe operators, or whatever the particular machine happens to be. This facilitates work station restructuring and/or cost-effective equipment modifications, where necessary. But, more importantly, it assures the individuals a much desired competitive edge by equipping them with the precise skills that local business and industry need. Thus, the training facility becomes a valuable resource for qualified employees, and a dynamic partnership is created.

As a trainee becomes ready for employment, the trainer, not a placement specialist, matches his skills with one of the existing job opportunities identified through the partnership with business and industry. This is another significant point that bears repeating. The ability to

compare an individual trainee's needs, skills and interest with an ever vascillating job market is crucial. Therefore, the trainer, not a placement specialist, does the matching and placement. If the trainers do the matching for the training process, it is only logical that they should do it for the placement process as well. Besides, it is the trainers who have experience in the skill areas being taught. They are familiar with the job market for these skill areas, and, they most certainly have the most knowledgeable working relationship with the trainee. Thus, when the trainer feels that a successful matching is possible, he approaches the prospective employer and discusses the trainee and his capabilities. The trainer also talks with the trainee about the potential for employment with that particular employer and company.

If an agreement is reached to try the job (evaluation?), the trainer accompanies the employee for a number of days, as needed (training?). The trainer must be absolutely satisfied that the employee is able to function on that particular job setting with the present co-workers.

In the event that a poor placement has been made, the trainer may take it upon himself to remove the employee from that employment situation before job severance has occurred and return him for further training. In this way, any deterrents to successful employment can be minimized and the trainee returned to the competitive work force. This process adds immeasurably to the credibility of the vocational development process and greatly heightens the satisfaction of employee and employer alike.

One final point needs to be made. Throughout the entire vocational process, in working with business and industry, we must use logic and persuasion. If we examine the role of the employer, it becomes evident that his primary role is to develop a marketable product, produce it as cheaply as possible so that it can be sold at a price that will be competitive, generate a profit, and maximize the potential output of all employees. Therefore, the employer's role is largely incompatible with that of providing training, and he would welcome trained applicants. Furthermore, being presented with a qualified employee reduces the risks involved with the unknown, off-the-street applicant. The bottom line is that we can guarantee greater job stability, less turnover and less time loss, with no loss in productivity, speed, or quality of work performed.

Few resources are available to business and industry to provide specific skill training and assistance regarding employment and employment practices for disabled workers. And, since employment in the real world of work is our pay-off criterion, our task, in the words of Thomas Carlyle, "is not to see what lies dimly at a distance, but to do what lies clearly at hand." It seems worth the effort.

JOBS FOR PEOPLE WITH EPILEPSY MAJOR EFFORT OF TAPS PROGRAM

by

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The delivery of vocational rehabilitation services to persons categorized under the general heading of epilepsy has and continues to represent one of the greatest challenges to the field of rehabilitation. The recent report of the National Commission for the Control of Epilepsy and its Consequences identified employment as one of the major problems to be addressed by governmental agencies at all levels.

Those of us providing vocational rehabilitation services need to recognize that the working community has not welcomed persons with epilepsy with open arms. Even those who are successfully rehabilitated do not appear to achieve the same level of employment as the population of rehabilitants as a whole. The need for more effective placement services is perhaps the only phase of the rehabilitation process agreed to by both professionals and clients.

There is little question that people with epilepsy who are able to enter competitive employment face barriers which are infinitely greater than those confronting persons whose primary handicap relates to architectural or other environmental factors associated with the work place or the job. In order to be employed, people identified as epileptic must be prepared to face bias and misunderstanding as well as the reality of the possible danger to themselves in the event of a seizure. Even if hired, they tend to enter and remain in jobs which no one else desires and with little, if any, opportunity for advancement into positions which truly are commensurate with their maximum vocational needs and potentials.

At the moment this condition is diagnosed, people with epilepsy become enmeshed in a system of myths, fears, misunderstandings and a lack of knowledge of how it and the person should be treated. Parents generally feel guilt and often frantically reach out to anyone who can offer a "magic" cure. Teachers may not know how to deal with seizures in the classroom and may subtly or overtly attempt to remove the child from regular classroom activities.

Peers may shun or make fun of the child, forcing him/her to be isolated in a hostile world. Physicians may suggest that the child will "grow out of it" or, even worse, be totally unaware of current treatment methods.

Social workers, psychologists, physicians and other helping professionals may give the parent and child conflicting information.

Society as a whole may, because of fears and myths associated with this condition, force the individual to become a second class citizen who will learn to be helpless. Even today, organized groups and individuals using the most sophisticated education techniques have not been able to significantly reduce the unrealistic fear about epilepsy. Consequently, it is not uncommon for the individual with epilepsy to deny the existence of the condition.

In a cooperative effort between the Department of Labor and the Epilepsy Foundation of America, the Training and Placement Service (TAPS) is funded by the Department of Labor utilizing CETA Title III funds. Seven metropolitan areas have been chosen by the Department of Labor to begin the task of developing employment opportunities utilizing on-the-job training funds with employers. They are Atlanta, Cleveland, Portland, San Antonio, Minneapolis-St. Paul, Boston and Puerto Rico.

Between 1949-74, a study was conducted by the Department of Labor to determine the direction of public attitudes toward epilepsy. Samples of the population were polled each year and the results were quite favorable. The question that was most pertinent to the TAPS Project was, "Do you think people with epilepsy should be employed in jobs like other people?" The number of people who answered "yes" increased over the 25 years the study was conducted.

However, in 1974 there remained 10,334,000 people who were opposed to persons with epilepsy working. Overall, the surveys indicated that most favorable opinions toward persons with epilepsy were among the better educated and employed, younger and urban residents.

The TAPS Project has approached the community in an innovative way in an effort to integrate schools, community and employment systems into a comprehensive support system for the client with epilepsy. The project coordinates these resources in developing a strong support network within the community to provide rehabilitation counselors, employers and clients with new and positive attitudes and assistance regarding successful placement of people with epilepsy.

The TAPS project works closely with vocational rehabilitation, focusing on complementing and supplementing what that agency is mandated to do rather than supplanting it. The coordinators work jointly in a cooperating manner with a positive approach to meeting client needs.

For more information on TAPS activities, contact the Training and Placement Service, Epilepsy Foundation of America, 1828 L Street, N.W., Suite 406, Washington, D.C. 20036 (202) 293-2930

A COMPETITIVE INDUSTRY OF SEVERELY DISABLED WORKERS

by

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In 1975, Center Industries Corporation officially opened its doors. This facility, located in Wichita, Kansas, is dedicated to the proposition that severely physically disabled persons, working alongside their able-bodied counterparts, can be productive in a competitive industrial environment. The company, under the auspices of the Cerebral Palsy Research Foundation of Kansas, Inc., is patterned after a similar effort in Sidney, Australia. It provides a buffer zone between the traditional workshop employment opportunities typically available to normal or near normal intelligent physically disabled persons and mainstream employment. Aide and attendant care is available to serve the human needs of the severely handicapped population, such as feeding, toileting, etc. A wage and salary administration program has been developed for the industry and handicapped persons receive compensation in direct relationship to their job description. Each person employed in the facility receives minimum wage or above.

Center Industries had approximately $1.2 million in sales for the year 1978-1979. For the year 1979-1980 it is projected that the organization will do approximately $1.6 million in sales. Center Industries Corporation manufactures license plates for the state of Kansas (approximately three million during the year 1978-1979), window assemblies for Boeing 727 and 737 airliners, farm implement tools, recreational vehicle struts, and a variety of job shop type products. In order to qualify for Javits Wagner O'Day government set asides and an SBA Handicapped Assistance Loan, the organization employes handicapped to able-bodied persons on approximately a 75%-25% ratio.

Many persons who are employees of Center Industries Corporation are also residents of the Timbers Project. This endeavor is a major HUD housing facility for severely handicapped people located in Wichita. Under the auspices of the Cerebral Palsy Research Foundation of Kansas, Inc., the Timbers serves and provides a residential environment for severely handicapped people. A transportation system is also available to take employees to work. Therefore, Center Industries Corporation, with its sister organization, the Timbers, provides an integrated setting for severely disabled people.

The above is a brief description of Center Industries Corporation itself. The employment procedure for Center Industries is described in the

following series of paragraphs. The catalyst for employing severely handicapped people in Wichita at Center Industries is associated with the Rehabilitation Engineering Center. This organization, funded by the Rehabilitation Services Administration, is a joint effort of Wichita State University, College of Engineering and the Cerebral Palsy Research Foundation of Kansas, Inc. Named as one of twelve National Rehabilitation Engineering Centers, the core area and objective of the Center is to provide vocational opportunities for severely handicapped persons.

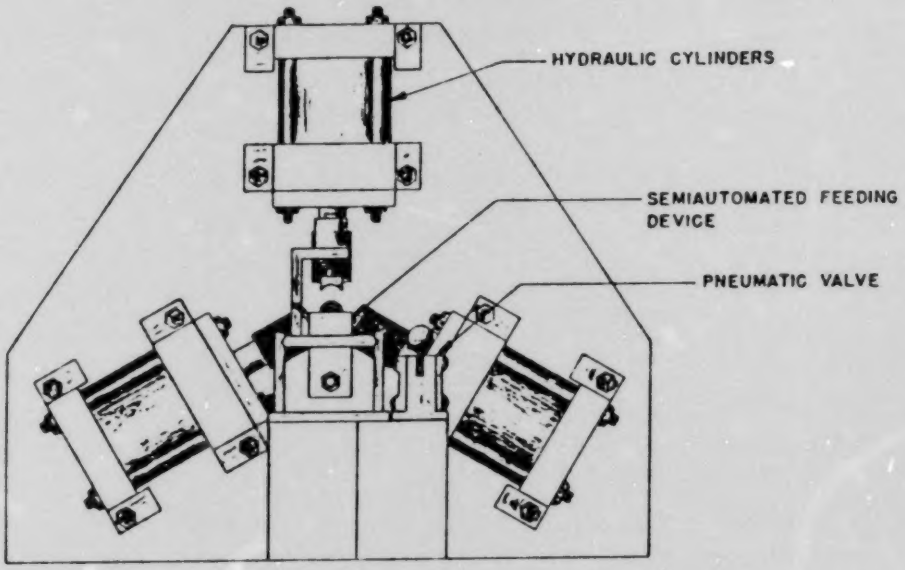
The research effort has been in existence since 1972 and has developed apparatus to determine the residual physical capabilities of severely handicapped people. This apparatus, called the AMI (Available Motions Inventory) is the first step in the employment process. Clients from throughout the state of Kansas arrive at the campus of Wichita State University and are tested utilizing the AMI to determine their feasibility for employment. After analyzing the AMI data and validating the medical, psychological and social history of the client, the severely handicapped person is admitted to the E.R.T. Unit (Evaluation, Research and Training Unit) at Wichita State University. This agency is designed to adapt severely handicapped people to jobs with Rehabilitation Engineering Center assistance and also to develop proper work attitudes in the handicapped population. When a job becomes available at Center Industries, people from the E.R.T. Unit are hired by Center Industries Corporation to fill a specific job slot which has received adaptation by REC engineers. While clients are in the E.R.T. Unit, they receive a minimum of 50¢ an hour with piecework paid for appropriate "real world" jobs. During the evaluation process, the COATS test is administered and various simulated work stations are evaluated utilizing the skills of the handicapped person. Once a handicapped person has been employed by Center Industries Corporation all other research entities are withdrawn and are not utilized unless needed in the job environment. In other words, the severely handicapped person becomes an employee of Center Industries Corporation and is subject to its rules and regulations through his or her departmental foreman. Cross training on jobs and subsequent adaptation for other jobs is the responsibility of the Rehabilitation Engineering Center.

This philosophical approach has proven successful in that, at the present time, approximately 40 severely handicapped people are employed at Center Industries Corporation in a wide variety of jobs. Many persons falling into the category of severely disabled need aide and attendant care and, therefore, mainstream placement is not a viable option to them at the present time. However, those persons who can tend to their own human needs are candidates for mainstream placement in Wichita industry with the help of the Rehabilitation Engineering Center. The Rehabilitation Engineering Center engineers are also active in adapting devices in a residential environment at the Timbers. It is felt that an integrated approach is necessary because a job is only one element in the existence of severely handicapped people.

The Rehabilitation Engineering Center staff works with the State Department of Vocational Rehabilitation in attempting to place people both at Center Industries Corporation and in a mainstream work

environment. The REC is also active in outreach activities in order to utilize rehabilitation engineering expertise on a statewide basis.

In order to demonstrate the approach utilized in placing severely handicapped people at Center Industries, the following example will be cited. Terry P. is a severely involved athetoid, quadraplegic cerebral palsied person. It was determined, several years ago, to place Terry on the job in a production line manufacturing recreational vehicle struts. In the manufacturing process, it was required to crimp a strut assembly at three different places, 120° apart. Prior to the modification of the job, three separate operations were required to produce the three crimps on a tube comprising the strut. From the analysis of the AMI data and the data generated by Terry's stay in the E.R.T. Unit, it was determined that he had only a minor pinch movement with the right hand. REC engineers, utilizing this data, developed an apparatus which requires a minimum amount of physical effort by Terry. He is responsible for picking up a tube, placing it in the holding device of the machine and activiting the machine. The machine clamps the tube, places it in the



THREE AXIS CRIMPER

crimping area, crimps the tube in three places simultaneously, and removes it for Terry's disposal. Without this apparatus, Terry could not have been employed. He is now making over minimum wage and is a productive member of the CIC team.

One problem associated with this type of effort is the cross training of severely handicapped people. In order to insure continued employment

for Terry, the recreational vehicle strut has to be a high volume, long-term contract commitment. Unfortunately, with the gasoline shortage, this has not been the case. It becomes a problem, therefore, to cross train and adapt Terry for other jobs within the plant. This is a distinct disadvantage of engineering adaptation of severely handicapped people for a particular contract but is, unfortunately, the name of the game.

In summary, it can be stated that, with proper rehabilitation engineering techniques, severely physically handicapped people can be employed in a buffer employment environment. Those people who can be mainstreamed with adaptive devices certainly should be given this opportunity. Center Industries Corporation, however, provides an intermediate step more sophisticated than a sheltered workshop but something less than mainstream industry. The aide and attendant care required by these people is a definite stumbling block to mainstream placement and Center Industries, in all likelihood, represents the best alternative for this population. The Wichita experience proves that severely handicapped people can be employed in a near normal work environment with their able-bodied counterparts. It provides the salary benefits of mainstream industry and able-bodied and handicapped people are able to mix in a work context. It provides income for the severely handicapped person at the minimum wage level and above and, more importantly, it provides the dignity of work.

REDESIGNING SHELTERED WORK ENVIRONMENTS

by

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Handicapped workers share with their normal peers the productive limitations of their inability to make decisions and judgments, require training time, are prone to make rejects, and produce at sometimes inefficient rates. Due to physical and mental handicaps, one or all of these production-related deficiencies may be more acute.

In order to compliment these productive deficiencies, manufacturers have developed a technology which compliments the productive nature of people and therefore meets the specialized needs of the handicapped worker. This efficiency technology utilizes the system of tooling and the use of stop blocks, fixtures, and jigs. These devices, when used in harmony with efficient work environments, provide for consistency in the product as well as the production.

Tooling limits the decisions and judgments of the producer, decreases the training time, decreases the reject rate, and increases quality productive output.

By understanding and incorporating the manufacturing technologies of efficiency, we can compliment the productive nature of the handicapped worker, provide broader and better output for our customers, and provide higher wage earning potential for handicapped workers.

This technology has been tested by time and merely awaits our employment of it with our people to benefit from our efforts as it has done for industry.

NEEDED: CREATIVE VOCATIONAL EVALUATIONS

by

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Job options for someone with a severe or complex disability, such as cerebral palsy, are sharply narrowed, not just by the physical concomitants of the condition. Low expectations for such individuals and use of largely inaccessible vocational evaluation systems contribute to a misleading and serious underestimate of their capabilities.

Our ignorance that mentally retarded workers can do complex jobs, and have shown ability to do so better than their nondisabled counterparts (GOLD, 72; 73), reflects our lower expectations. People with even more disabling conditions face similar, if not lower, expectations. The result is that we may close opportunities through ignorance. By never expecting individuals to hold jobs, or hold high level jobs, we will not make it possible for them to do so.

Others as well feel that commercially-available worksamples shortchange severely disabled persons. Twenty-five years ago the Cerebral Palsy Work Classification and Evaluation Project and Follow-up Studies (MOED & LITWIN; YUE & MOED) were undertaken precisely because they considered TOWER worksamples "too difficult" for cerebral palsied persons. Interestingly, they were exclusively serving the "more adequate of the cerebral palsy population," or less severely disabled. They chose to spend considerable time identifying "feasible" jobs in clerical and industrial areas and then in devising new worksamples. We feel this narrowed job possibilities and perpetuated the system that effectively screens out severely disabled persons, rigidly followed and timed worksamples.

Although formidable obstacles emerge in both administering worksamples to the more severely disabled and in interpreting the results, we feel it is better to adapt than to scrap the systems. Wheelchair mobile people who cannot reach the upper mail boxes as set up for TOWER mail sorting worksamples, often are not evaluated at these tasks. Is this to say that such a person is unable to do a job that requires mail sorting? Of course not, although vocational evaluators often reach such a conclusion. Without examining the individual's skills we do not know whether he or she could do it. To be able to check the person's ability with the worksample, one might try lowering the mail boxes or sorting mail on a flat table surface. However, when such changes to the worksample are made, they invalidate the test. Even though changes are described in the report,

interpretation becomes difficult. For example, if a person cannot manually do a task within time limits, but can do so with an aid or by operating a machine, is he or she competitively employable? Thus, our "Catch-22" of evaluating severely disabled persons:

> *If worksamples are administered strictly according to protocol, no information is gained; if changes are made, the predictability is invalid.*

Consider, then, the experience of individuals whose conditions are compounded by tremors, uncontrolled movements, weak grasp, perceptual difficulties, poor hearing, or unclear speech. They challenge evaluators with inability to manipulate or even reach tools or worksamples as customarily set up... with slow movements or unclear speech that may hide rapid grasp of an idea or intelligent thinking... with an educational background stifled by inability to write with a pen or turn a page alone... with social experiences limited by inability to go out of the house or handle money...

How, then, does one vocationally evaluate a severely disabled person?

This article presents the approach developed by our Job Development Laboratory (JDL). Our approach is characterized by problem-solving and uncovering of skills and rests heavily on detailed information about local jobs. It grew from a project involving clients considered "too severely disabled for employment" by their state vocational rehabilitation agencies. The JDL placed 76 out of 116 of such individuals into competitive jobs (MALLIK & YUSPEH, 1979) and subsequently worked with peopled disabled by cerebral palsy and other multiply-handicapping developmental conditions (MALLIK & SHAVER, 1980). As a result, clients unable to manage a pen or pencil were nonetheless able to hold full-time, competitive jobs!

Experience in these and other projects persuaded us that, used conventionally, vocational evaluation techniques such as worksamples, situational assessment, "paper and pen" aptitude and interest tests, and manual dexterity tests were grossly inadequate at uncovering the types of jobs a severely disabled person could do and the ways in which she or he might be able to do them. Here is a rundown of problems we identified with conventional approaches to evaluation, along with changes we made and recommend. Where pertient, support for these methods by other researchers is included.

- *Conventional work sample systems simply do not reflect our (and likely your) local job market, shifts in hiring, or types of locally-available jobs most suited for severely disabled persons. In fact, we sometimes feel the worksamples are irrelevant to a severely disabled person's prospects for employment!*

The solution, we feel, is to have available during evaluation (a) detailed job information, and (b) information about aids or methods to assist in doing jobs. Genskow paraphrases an old test adage that underlies our use of this information:

> The closer the test is to what it is supposed to be testing, the better the test.... In vocational evaluation, there is no situation that resembles a job more than the job itself. (GENSKOW, p. 22).

During our evaluation, a heavy emphasis is placed on identifying actual job tasks, on seeing how well a client can perform them, and on determining ways to enhance his or her performance so that it is competitive.

• *Conventional approaches to vocational evaluation discourage exploration of alternatives which is crucial to job placement of many severely disabled persons. Time constraints, rigid systematization, and reliance on a single evaluator who is likely untrained in adaptive aids, stifles the evaluator's creativity in working with severely disabled persons, and has the effect of underestimating the client's potential.*

We use worksample systems flexibly to gain information, which means taking time to try ideas generated by staff members on alternatives that might improve the client's performance. We then weigh their performance against our knowledge of realistic job options and demands. This process effectively taps the collective expertise of the staff.

All of our staff are on-hand during the evaluation, to brainstorm about ways to enhance the individual's performance. The job placement specialist knows (or can quickly find out) about local job availability, job tasks and other specifics. The occupational therapist knows methods and aids to enhance physical functioning and independent self-care, and where to buy or how to make many such aids. The rehabilitation counselor/evaluator knows how to facilitate adjustment to the disability, to work and to aids; test interpretation; and community resources. The rehabilitation engineer knows how to conceive and make specific work aids, and where to find them if they are commercially available.

Our evaluation process involves the following steps. • The entire staff analyzes background data of the individual to determine factors that affect employability and identify skills to be explored during the upcoming vocational evaluation. • "Critical tasks" of prospective jobs are set up by the staff using worksamples and information from job task analyses. Ordinary office equipment is used, since most jobs in this community are office-oriented. In this manner, detailed aspects of the prospective job are not overlooked. • The client is asked to perform tasks. The staff observes the performance, often interrupting it to freely discuss with the client and try alternatives that may improve his or her performance. Alternatives may include repositioning or stabilizing work materials, trying another method such as feet rather than hands to accomplish a task, using different equipment or control switches, planning a more efficient workflow set-up, or mocking up a customized aid for someone. All staff members participate in this informal trial and exploration. The job placement specialist and rehabilitation counselor are particularly helpful in weighing the performance against employer demands. • While the individual is trying these job simulations and alternatives, ideas about additional job possibilities are generated and explored. • A visit to the client's

home is made to resolve any difficulties that have a bearing on work, such as dressing oneself in a timely manner. • Some potential job skills and recommendations are identified by the end of our vocational (1-2 days) and home site (1 day) evaluations. However, our evaluation does not stop here, as is generally the case. Our approach is unique in its marriage to job placement, and this involves further steps in our process. • We generally expect to see the individual on subsequent occasions to focus on specific job options. This extends even beyond job placement, and encompasses future job changes and activities at the home that have a bearing on work.

• *Used conventionally, vocational evaluation systems are often inaccessible to severely disabled persons.*

The wheelchair-mobile person mentioned earlier demonstrates one type of "access" problem, or problem even trying to do the worksample, that of reach. By permitting access, or changing the height of the mailboxes, the evaluator can examine the individual's skill using the worksample materials. Moreover, the client sees, and is motivated by, this attempt to enhance his or her performance. A few other examples of ways to provide access to the worksamples include relocating materials and tools for reach (i.e., if one-handed, in a semicircle around that hand), using height-adjustable tables (different heights may be necessary for each person), and reading instructions aloud for visual or perceptual difficulties that impair reading but not performance.

• *Vocational evaluators often "fail" to accommodate severely disabled persons.*

Employers are now required by law to make "reasonable accommodation" to allow a disabled person to perform a job, yet vocational evaluators seldom, if ever, do so. We feel this is due, in large part, to evaluators' lack of knowledge about alternatives and, in part, lacking a sincere appreciation for the limitations as well as the strengths of testing. Our experiences have taught us such an appreciation, shared by others:

> In point of fact, most human beings possess capabilities that can be developed into a job skill. That tests cannot always bring out this skill or aptitude or achievement is not the fault of the individual, but represents a shortcoming of tests themselves (BURKETT, et al, p. 90).

Again, our task in vocational evaluation of severely disabled people is to determine what types of jobs they can do and how they can most ably do them, not simply how well they perform on the worksamples at hand.

By accommodation, we are talking about providing alternatives that will enable an individual with potential to learn or to do a job. To us it means exploring alternate methods, commercially available and custom-made aids, different equipment, personal flexibility, and to some extent

training during the evaluation process. Botterbusch clearly points out, in his discussion of how to accommodate for three disabling conditions (mental retardation, blindness, deafness), that the individual's life history may affect the test results, may be substantially different than the people on whom the test was normed, and needs to be considered in test selection, administration, scoring and interpretation. This is especially important in the case of people with developmental conditions--where motor impairment may have a cumulatively limiting effect on the acquisition of other abilities common to people of the same age:

> To have a client take a test before he is aware of what is involved, to have a client not understand the instructions, to have a client miss items because he cannot perceive them, to have a client "fail" a test because the format of the items way beyond his comprehension is to invalidate the test results ... (BOTTERBUSCH, p. 1).

We suggest that the norms are violated simply by severity of disability. The changes we advocate do violate the "predictive validity" of tests ... the validity, recall, of inadequate tests. Yet without such changes we are discriminating against the very people we are struggling to serve.

Clearly we must try "accommodating" a person to avoid underestimating his or her potential, and we rely on our professional judgment to determine if the individual has employment potential. Our own expertise about local jobs and job requirements is certainly more accurate for our job market than is that of the worksample manufacturers, especially when we are also engaged in selective job placement. We use the worksample performance standards, or norms, as rough guides about the effectiveness of our interventions. Still, our inferences boil down to highly educated guesses--guesses about level of performance and whether further improvement can be expected via practice, training, therapy or purchase of aids. Hence, the reason for our subsequent reevaluations: to determine if sufficient improvement has occurred (after training, etc.) and, if not, how else we might try to improve the individual's performance. Specific suggestions for accommodating to compensate for cerebral palsy are listed at the end of this article.

- *Conventional vocational evaluation approaches often overlook "details" such as transportation that have a critical bearing on job placement of severely disabled persons.*

Our approach is first to take a broad look at "circumstantial" factors that affect employment, and to consider what steps yet need to be taken to resolve or lessen them. This includes such diverse concerns as accessibility of the home or office site, transportation to and from work, financial disincentives, emotional adjustment, and ability to toilet independently. The Functional Limitations Scale that Crewe, et. al., developed as a tool for rehabilitation planning and counseling similarly reflects broad, general concerns that affect employability.

We obtain this information through interview, observation, and a visit to the home. The home visit is important for several reasons. First to determine the actual level of functioning, for we have often found individuals helped to become "ADL (activities of daily living) independent" at accessible comprehensive rehabilitation centers often are not so once they return to their inaccessible homes, and this ultimately affects their employment prospects (if someone living alone cannot dress independently, he cannot get ready for work each morning). We strongly believe someone need not be ADL-independent to work. However, we need to identify the constraints that must be considered for job placement planning (i.e., bars for toilet transfers) if that is the case. Second, alternative methods of resolving work-related self-care problems are explored. Third, in some cases the home site is examined for potential as a work site.

Due to the highly individual way in which cerebral palsy manifests itself in an individual, it is necessary to take a detailed functional look at an individual. Ambulation, speech, hearing, movement, and perception may be uniquely affected for each person. Further, the impact of these disabling factors varies with the occupations being considered by someone. Inaccurate finger movement has a different meaning to an attorney than to a machinist. Defining the condition in detailed functional terms allows us to compare the individual at a future time with tasks required on prospective jobs, or person-job matching.

Our approach is comprehensive and detailed, functionally-based and problem-oriented. The result is a comprehensive rehabilitation plan, with contingency plans, that pinpoints problems and outlines recommended intervention strategies. In fact, it is precisely this comprehensive rehabilitation plan, often designed for selective job placement, that permits one to see that job placement is "realistic."

The following are suggestions we feel help uncover job skills and ways to enhance the job skills of persons severely disabled by cerebral palsy. They are ways of accommodating for the disability. They need not be applied in every case, as they are not always needed, but your attention is called to them because they are generally omitted from conventional evaluation practices.

1. Incorporate into the evaluation an awareness of current job openings, changes in openings, aids and other methods to enhance the client's abilities. Include time to explore these.

2. Cut out or reduce distractions, such as excessive noise and people interrupting.

   These are discouraged in all testing situations, but they are even more debilitating to persons whose conditions predispose them to be easily distracted, or to have more exaggerated movements in response to loud noises or sudden movements. Because muscle tension is such an integral aspect of cerebral palsy, we do everything possible to counterbalance or minimize it, including encouraging a relaxed atmosphere to lessen possible "test anxiety."

3. Reposition and stabilize the individual and work tools or materials.

The rationale behind repositioning and stabilizing people with cerebral palsy is to make movement as normal as possible--to help the individual access work, make maximum use of the diminished reach and voluntary control he or she possesses, and minimize fatigue (TROMBLEY & SCOTT: FINNIE). This idea is to identify ways to compensate for abnormal movement. For example, we have observed that the excess motion characteristic of cerebral palsy not only impairs accurate movement, but distracts the individual, making him or her even slower. This was dramatically illustrated by an individual whose typing speed doubled from 4 to 8 w.p.m. solely by repositioning him to eliminate leg and arm movement. Many aids are commercially available, such as forearm rests for typewriters, viewers, typewriter keyguards, special chair backs and seat inserts, and Dycem friction material to stabilize objects. Occupational and physical therpists may be helpful in maximizing physical functioning through aids and alternate methods.

4. Separate learning from performance and provide opportunity for learning to compensate for developmental delays and physical disability.

There is much evidence that careful training can overcome developmental delays that impair a client's performance, such as ability to learn. Gold (73) has demonstrated this with one-to-one training of retarded workers, as have Brolin and Koska. One-the-job evaluations are an extension of this idea, allowing an individual to become fully accustomed to the job, tasks, and environment. Physically disabled people, as well, often need time to accustom themselves to doing a task differently (TROMBLEY & SCOTT). Someone whose muscles were never coordinated may fear failure and have difficulty mastering even a new method or using an aid. We need to separate learning from performance, and allow time for learning to take place. Sometimes we accomplish this by allowing extra time for the individual to practice during evaluation, and other times we suggest the individual practice or learn the task on their own and come back later for reevaluation.

5. Approximate the potential job task(s) and tools as closely as possible--when evaluating (via job simulation and job trial).

6. Look for alternate methods for doing a task, before seeking a device or aid.

A method is more portable. Look for the simplest, easiest, and most cost-effective solution if an aid is necessary.

7. Look for ways to make the job as efficient and causing as little fatigue as possible.

Cerebral palsy is a condition characterized by expenditure of much energy (via uncontrolled movement), so conserving energy is an important strategy to such a person. Setting up tasks efficiently helps compensate for delayed movement. Motion-time-measurement is one industrial approach to achieve efficiency; it emphasizes

techniques that lend themselves well to the needs of those disabled by movement impairment, for example, sliding items rather than picking them up, and using stop-blocks rather than measuring.

8. Consider "details" that have a bearing on employment, such as transportation, toileting at work, etc.

9. Learn about local jobs that require cognitive or perceptual skills rather than manual ones.

10. If necessary, reevaluate the client's performance after practice, training, therapy or purchase of aids to monitor improvement and make further suggestions.

REFERENCES

Botterbusch, Karl F. The Use of Psychological Tests with Individuals Who Are Severely Disabled. Menomonie, WI: University of Wisconsin-Stout, 1976.

Brolin, Donn and Charles Koska. "Critical Issues in Job Placement of the Educable Mentally Retarded," Rehabilitation Literature 35(6), (1974), pp. 174-77.

Burkett, Lowel, et. al. "Bread and Fire," American Vocational Journal (January 1973), pp. 90-100.

Crewe, Nancy M., et. al. "Vocational Diagnosis Through Assessment of Functional Limitations." Archives of Physical Medicine and Rehabilitation 56 (December 1975), pp. 513-16.

Finnie, Nancie F. Handling the Young Cerebral Palsied Child at Home, 2nd ed. New York: E. P. Dutton, 1975.

Genskow, Jack K. "Evaluation: A Multi-Purpose Proposition," Journal of Rehabilitation (May-June 1973), pp. 22-25.

Gold, Marc W. "Factors Affecting Production by the Retarded: Basic Rate," Mental Retardation 11(6) (1973), pp. 41-45.

Gold, Marc W. "Research on the Vocational Rehabilitation of the Retarded: The Present, the Future," in N. R. Ellis (ed.), International Review of Research in Mental Retardation, Vol. 6. New York: Academic Press, 1972.

Housman, R. and D. Smith. "Placement for Persons with Severe Disabilities," Rehabilitation Counseling Bulletin 18(4) (June 1975), pp. 245-53.

Machek, Otakar and Hardin A. Collins. "Preliminary Report of Evaluating and Classifying the Vocational Potential of the Cerebral Palsied," Archives of Physical Medicine and Rehabilitation 41 (1960), pp. 434-37.

Maki, Dennis R., et. al. "A Systems Approach to Vocational Evaluation," Journal of Rehabilitation (January/February/March 1979), pp. 48-51.

Mallik, Kalisankar and Elaine Shaver. Technical Support Services to the Developmentally Disabled in Region III: Final Report. Washington, D.C.: The George Washington University, 1980.

Mallik, Kalisankar and Sheldon Yuspeh. Job Development and Enhanced Productivity for Severely Disabled Persons. Washington, D.C.: The George Washington University, 1979.

Moed, Martin and Dorothy Litwin. "The Employability of the Cerebral Palsied: A Summary of Two Related Studies," Rehabilitation Literature 24(9) (1963), pp. 266-71.

O'Reilly, D. Elliott. "Over 21 and Cerebral Palsied," Presidential Address presented at the American Academy for Cerebral Palsy, November 17, 1974.

Rosenberg, Bernard. "The Use of Work Samples for the Cerebral Palsied," Vocational Evaluation and Work Adjustment Bulletin 5(1) (March 1972), pp. 18-21.

Rosinsky, Robert W. "Evaluating the Severely Disabled: The Controlled Environmental Laboratory Evaluation," Rehabilitation Literature 36(10) (October 1975), pp. 302-05.

Trombley, Catherine A. and Anna D. Scott. Occupational Therapy for Physical Dysfunction. Baltimore: The Williams & Wilkins Co., 1977.

Yue, Shyn-Jong and Martin Moed. "Medical and Vocational Evaluation of Young Adult Cerebral Palsied: Experience and Follow-up, 157 Cases," Archives of Physical Medicine and Rehabilitation 41 (1960), pp. 136-142.

SECTION II

ENHANCING FUNCTIONAL INDEPENDENCE

SPECIALIZED SEATING AND MOBILITY - TECHNICAL CONSIDERATIONS

by

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I. SPECIALIZED SEATING

This task was conceived to address this urgent clinical need through the design development of standardized techniques and related hardware utilizing currently available technology and industrial practices. Assuming success in the first phases of the task, the second phase of the project was to identify remaining problems requiring basic investigation and to initiate studies accordingly. Development of this task has followed that plan, and has resulted in the development of two complimentary seating systems; the Modular Plastic Insert System (MPI) and the Foam-In-Place Seating System (FIP). In addition, and as a result of experiences gained with the above two systems, a simplified add on trunk support device termed the Spherical Thoracic Support was also conceived and developed. Finally, a number of irresolvable problems were defined and a basic research study developed which addresses the deficiences in clinical knowledge in the area of specialized seating and positioning of physically handicapped children.

The Modular Plastic Insert (MPI) System was designed for those preadults confined to wheeled mobility that have moderate physical involvement; usually as a result of cerebral palsy. The MPI System is comprised of a multi-adjustable measuring chair complete with a series of standardized vaccum-formed plastic modules, which can be readily assembled and inserted into a variety of wheeled bases. (Fig. 1) The measuring chair permits the assessment of the child prior to the provision of a seating system, in order to assist in decision-making and the transfer of vital information from therapy to technical staff.

The second system, the Foam-In-Place (FIP) System, was developed for the more severely involved person and permits the rapid fabrication of customized foam seating components. The FIP System is a newer development which utilizes two component flexible polyurethane foam, formed directly around the individual supported in the corrected seated posture. (Fig. 2 & 3) The Spherical Thoracic Supports (STS) are fabricated from two component polyurethane foam in standardized molds, and can be attached to any standard wheelchair by use of adjustable hardware which is positioned to provide lateral trunk support as required. The design

features a novel spherical joint which allows positioning of the pad to accomodate the contour of the users thoracic cage. (Fig. 4 & 5)

The major effort this past year in the MPI system has been the conducting of an external evaluation of the system, involving seven clinical centers. Forty units were fitted and evaluation carried-out following a structured evaluation protocol provided to the evaluating clinics. The evaluation data has been compiled, priorities on design refinement have been established, and the results of the evaluation process have been published and are available upon request. The design development and formal evaluation of the MPI System is now considered complete. Further design refinements to the system will be done with the involvement of a prospective manufacturer, so that any design changes will be compatible with the specific capabilities of the manufacturer.

The mauor effort with the Foam-In-Place during the past year have been to investigate potential health hazards that may exist with the use of polyurethane foam, when palmerized in close proximity to a user. The first approach taken was to re-establish contact with the supplier; the Upjohn Company, and seek data compiled by the manufacturer on health hazards studies. The second appraoch has been to work with the University of Tennessee - Materials of Science Technology Laboratory; in which extensive Agar Overlay tissue culture studies were done on fresh samples of polyurethane foam, palmerized in a manner identical to the Foam-In-Place application with human subjects. Control studies were done utilizing three samples of polyurethane foam materials used routinely in everyday applications; one sample being a commercially available polyurethane wheelchair cushion. The results from the tissue culture tests essentially support the claims made by the manufacturer. Specifically, the tissue culture study indicated that:

1) The toxicity of the polyurethane foam used in the Foam-In-Place application (CPR 1947N) is consistent with the foam used routinely in furniture and commercially marketed wheelchair cushions.
2) The latex film which provides a barrier between the patient and the foam is itself non-toxic.
3) Toxicity decreases significantly through time. Comparative studies involving the comercial foam samples and the CPR 1947N formulation were done within a two week time period.

The third approach has been to conduct an extensive review of the literature in particular, to seek out information on the toxicity potential of methylene biphenylocyanate (MDI) in comparison to diisocyanate (TDI). The literature clearly states that MDI which is used as the isocyanate component for the CPR 1947N, has greater molecular weight and significantly lower vapor pressure at room temperature than TDI; thereby reducing the vapor hazard potential which is consistent with commercial applications using foams with the TDI isocyanate component. Incidentally the TDI isocyanate system has been the polyurethane system used by prosthetists in prosthetic fabrication for many years.

The final step has been to conduct an onsite analysis of the vapors present both in the area of the technician and the subject. These have been done using a mass spectrograph which yields a PPM indication of toxic agents in the air. The preliminary results of this study have indicated that there are no toxic agents approaching dangerous levels in the air, either during the mixing by the technician or during the foaming in the vacinity of the subject. As a result of the above testing our preliminary conclusions are; "with proper recognition of the risk, application of suitable safety precautions, proper conditions of use, and good housekeeping practices, polyurethane and polyisocyanate plastic materials can be, and many millions of pounds have been, applied with no apparent harmful effects". A preliminary report on the Foam-In-Place procedure and the health hazards investigation has been compiled and is available upon request.

As previously discussed, the MPI, FIP, and the STS systems have been developed in response to clinical needs that could be addressed through applied research utilizing available technology. These new systems provide benefits in terms of improved comfort in seating, enhanced positioning, and increased mobility. However, before the design of tehse types of systems can progress towards the resolution of the remaining problems affecting specialized seating, a deeper understanding of the neuro-motor responses induced or inhibited by a seating device is required. Affects of body segment positioning, location of external force application, center of gravity orientation, and affect of non-contact external stimuli are of prime importance. Plans have been laid for the initiation of a basic study to investigate and clarify a number of basic therapeutic principles as they relate to specialized seating. A second and parallel approach will be to define and verify new variables which inhibit or induce spasticity in cerebral palsy. Specifically, the variables of temperature, noise, light, texture of support surfaces, and the attitude of the body in space will be investigated as to there effect on spasticity in a seated position. Assuming support is provided for this project it is anticipated that the required measurement instrumentation will be designed and constructed by 1980 year end. Formal trials with research subjects will begin in 1981 and be completed in 1982.

II. MOBILITY FOR SEVERELY HANDICAPPED CHILDREN

Education and vocational pursuits are often only possible for severely involved non-ambulatory individuals after they have achieved some form of independent mobility. For the very young, exploration of their environment can be greatly enhanced through simple mobility devices. Other mobility devices can greatly reduce the effort required to transport a dependent child or adult from the home into the community. For others mobility devices such as powered wheelchairs, offer tremendous potential for independence which is so essential in educational and vocational pursuits.

In order to address this diversity of needs this task has been organized in three distinct, but related areas of need; each with increased degrees of technical complexity and investment in research and development

resources. The three project areas are a) developmental devices (short term); b) transport devices (intermediate term); and c) powered mobility (long term).

A. Developmental Mobility

The initial major focus of this task has been to investigate alternate approaches to providing mobility and increased independence for children and young adults born with myelomeningecele. Traditionally efforts to provide mobility for this population has focused on full lower limb orthosis (HKAO) and ambulation with walkers or crutches. Generally, this approach has been expensive and does not yield an acceptable long term result in that a high percentage of these individuals opt for a wheelchair, either late in the first decade, or early in the second decade in life. The approach taken has been to define the needs as related to three childhood developmental stages: pre-school, school age or pre-teen, and teenage to adulthood. Initial efforts are focused on the pre-school and school age population; ie, phase one and phase two. There specific needs were defined by conducting investigative meetings with clinical personnel, in addition to questionnaries being sent to parents, school teachers, and other professionals in the community.

B. Phase I - Plastic Upright Positioner (PUP)

Initial focus on phase one has resulted in the design and development of a novel body support and mobility system termed the Plastic Upright Positioner (PUP) for the pre-school age group. The main feature is its simplicity. The design comprises two modules; a) a body support module, and b) a multi-purpose wheeled base module that interfaces with the body support.(Fig. 6) Body support components are designed in three standard sizes made from vaccum-formed ABS thermal plastic. The wheeled base is produced in one size in such a manner that it will interface with the three sizes of body modules. The combined body support system and the wheeled base provide a versatile, low cost system for the mobility management of pre-paraplegics. (Fig. 7)

C. Phase II - Sitting/Standing Mobility

Needs assessment studies indicated that the pre-teenage (6-12 years) population have needs that are significantly different from those of the pre-school child. That is, independent sitting and standing, transferring, hygiene care and increased mobility are needs that rapidly emerge in importance when the child leaves the home environment for longer periods of time. As a result, phase two design criteria calls for development of a system which will combine the advantages of upright mobility, normally achieved with HKA orthosis or the PUP system with those advantages gained by utilizing wheeled mobility such as that provided by a wheelchair. That is, a multi-purpose mobility/standing device. It was felt that the key of success of this multi-purpose sitting/standing/mobility device was the development of an efficient drive system that could be affectively operated by an individual either in the seatted or standing position. To this end, a prototype Posidrive

System has been developed and incorporated into a standard wheelchair for purposes of evaluation and laboratory testing. (Fig. 8)

During the past year the Posidrive concept has undergone laboratory evaluation in two external facilities. Initially, the Posidrive System was shipped to the Rehabilitation Engineering Center in Charlottesville, Virginia where extensive energy consumption studies were carried out. The results of these studies have been documented and are available upon request. In summary, the evaluation study indicated that the Posidrive System is not as efficient as conventional wheel/rim propulsion and that losses are due primarily to drag and friction in the drive assembly. More recently, the Posidrive System has been sent to the Tufts New England Medical Center-Rehabilitation Engineering Center for evaluation under laboratory conditions. Results of this second evaluation are expected in the near future. The ultimate goal being to develop an efficient drive system that can be operated effectively in both the seated or standing positions.

D. Transport Devices

The purpose of this task is to develop concepts and related devices that will address the problem experienced by parents and attendants in transferring older dependent children in family vehicles or in school buses. The initial focus of this project has been the development of a concept to facilitate the transfer of children to family vehicles. The Travel Base concept facilitates the transfer of the child, complete with their seating system into the family vehicle. The wheel assembly detaches from the seating module for trunk storage after transfer has occured. (Fig. 9) This approach is similar to the commercially available Travel Chair, however, the commercial devices features a reclined sling seat which does not adequately accomodate many children requiring special positioning. The new Travel Base will accept the MPI, FIP, or other custom seating components. During the past six months three of the Mark III designs have been produced and introduced to local field tests. The Mark III design features several design improvements including an adjustable thigh length, interior/posterior head support, adjustable foot rest, and a foot operated brake. Parent responses are being closely monitored to determine if this unit is ready for wider trials.

E. Powered Mobility

The purpose of this task sub-task is to develop concepts and related devices that will permit individuals to control powered wheelchairs that lack the necessary neuro-motor function to use the conventional controls.

Four alternate types of control have been developed and tested by severely involved individuals requiring independent mobility. These controls utilize the head, the hand, the foot and a combination of head and hand to control modified powered wheelchairs. This experience led to the formation of a new approach to powered mobility control for the severely neuro-motor impaired.

The conceptual approach now being investigated is based on the fact that many individuals that require specialized wheelchair controls often have requirements to control many additional powered devices in their environment. That is, the concept takes a global view of control encompassing the control needs of the wheelchair, communication aids, and environment control devices, electronic workstations, etc.; and integrates the hardware options into a system with a micro-processor as the central control module. That is, the concept takes the modular approach to control in which the micro-processor provides the essential client hardware matching and master control; to be interfaced with a variety of peripheral slave devices depending on the needs of an individual. A prototype unit has been assembled for purposes of demonstrating the potential of the concept. (Fig. 10) The further development of the system will be dependent on availability of research funds. A more detailed concept paper has been prepared and is available upon request.

FIGURE 1:
The Modular Plastic Insert System inserted into a commercially available wheeled base (Pogan Buggy).

FIGURE 2 (Below):
In the Foam-In-Place process, two component polyurethane foam is mixed and poured into a mold mounted on a foaming chair. A latex sheet provides the barrier between subject and pressurizing foam.

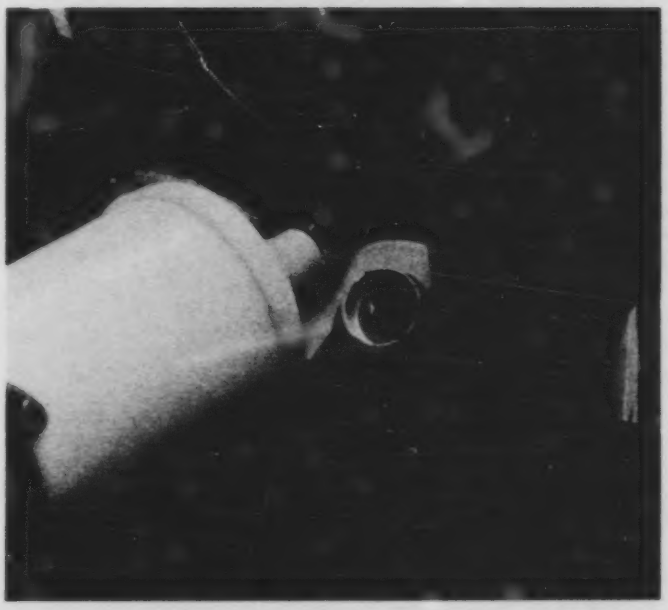

FIGURE 3:
Both customized seat and back components can be quickly made using the foaming chair. Covering with two-way stretch fabric and interfacing into the wheelchair complete the process.

FIGURE 4 (Below):
The Spherical Thoracic Support attaches to the posterior upright of all standard wheelchairs with adjustable hardware that permits 3 degrees of adjustment of the support pad.

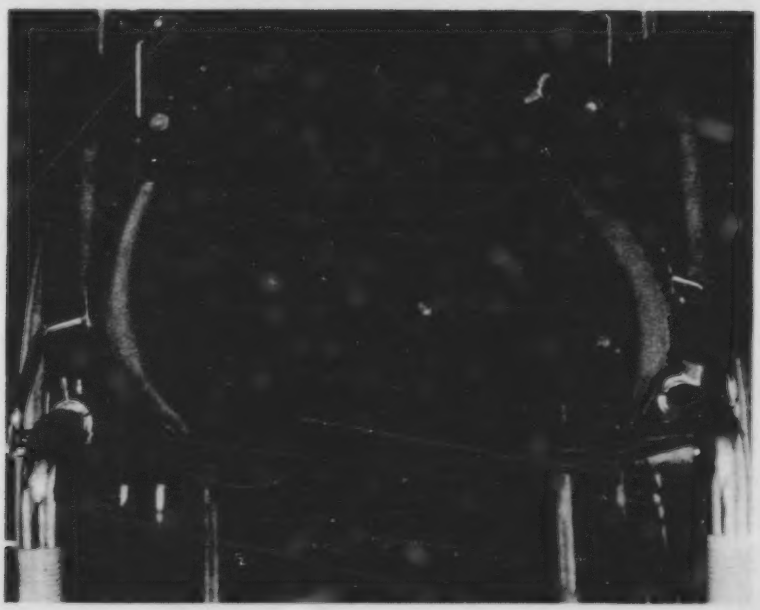

FIGURE 5 (Above): The STS provides add-on lateral trunk support for individuals who require support in addition to that provided by the wheelchair.

FIGURE 6 (Right): The Plast Upright Positioner is vacuum-formed in three standard sizes and may be used as an independent body support device, or combined with a wheeled base for greater versatility.

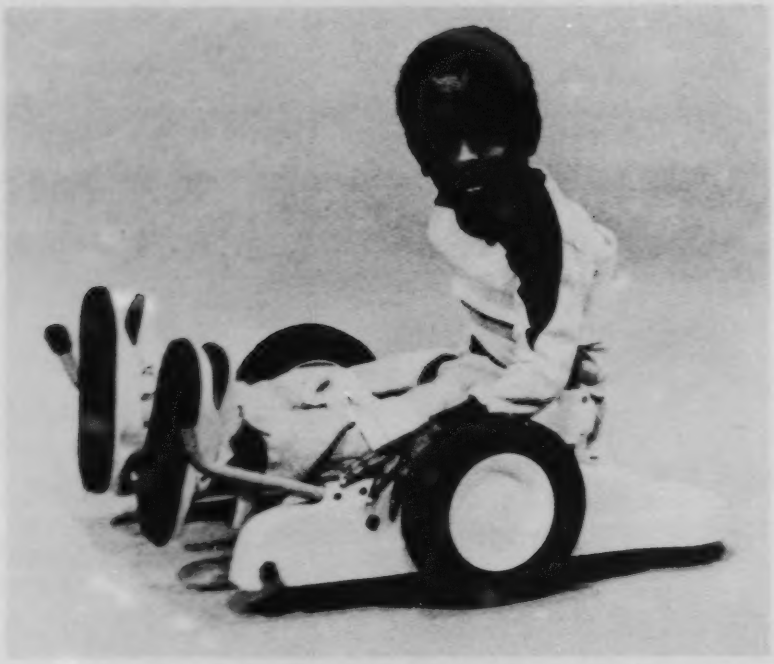

FIGURE 7 (Above):
The PUP system also may be used in the seated position to provide indoor mobility in homes and educational settings.

FIGURE 8 (Right):
The Posidrive concept utilizes a positive-drive belt and clutching mechanism to deliver power to the wheels. Energy consumption studies have been conducted to evaluate the efficiency of the drive system compared to direct wheel/rim propulsion.

FIGURE 9 (Right):
The Travel Chair facilitates the transfer of older children into the family vehicle. Wheel assembly detaches for storage in the trunk.

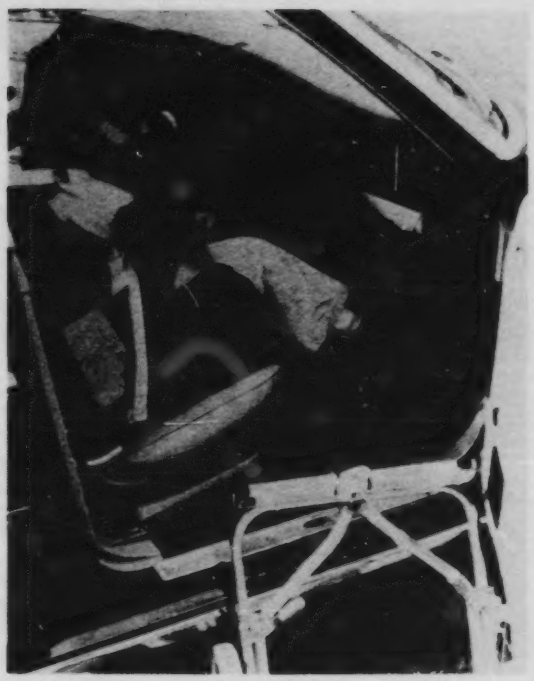

FIGURE 10 (Right):
The MK I prototype of the micro-processor control concept, incorporated into a powered wheelchair. Control is achieved by pointing the head mounted sensor and an L.E.D. feedback panel.

8.

SYSTEMS FOR INDEPENDENT MOBILITY

by

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"ACCESSIBILITY WITHOUT MOBILITY IS AN EFFORT IN FUTILITY." This statement made at a recent Transportation Research Board meeting by a young quadraplegic woman, clearly states a reality of daily living for the handicapped. She was expressing the frustration of not being able to use accessible facilities because she could not get to them. There are many severely disabled individuals with the same problem. Despite the good intentions registered in Section 504 of the Rehabilitation Act of 1973 to make public buildings and transportation systems accessible for the handicapped the reality of use is dependent upon the ability to reach the accessible facility or transportation system.

Controversy has developed over the Department of Transportation regulations related to Section 504. Prompted by the staggering costs related to compliance and the question of benefit related to patronage, the American Public Transit Association has challenged the regulations in court. (The decision is pending at the time of publication.) In question is the civil rights issue of accessibility of all transportation systems regardless of cost and benefit. Opponents of the civil rights concept generally support the theory of social integration--i.e., funds are best invested in transportation systems which provide service as required by individual need.

In view of this controversy, legislators are critically studying the implementation of transportation services to the disabled. Alternative approaches which would be consistent with national, social and economic objectives are being identified. The Congressional Budget Office, at the request of the Senate Budget Committee and the Transportation Subcommittee of the House Public Works and Transportation Committee, has developed a Budget Issue Paper for Fiscal Year 1981 entitled Urban Transportation of Handicapped Persons: Alternative Federal Approaches.[1] The paper identifies three alternatives for diminishing the travel problems of handicapped persons (1) The Transit Plan, (2) The Taxi Plan, and (3) The Auto Plan. Each plan is compared and evaluated in the report. It is significant to note that this is the first Congressional budget issue paper which presents a plan that would give a capital grant to non veteran disabled individuals to cover the purchase price of specially adapted private cars or vans.

The rehabilitation community enthusiastically receives the news that public awareness is being directed toward alternative mobility solutions for the disabled. We have long known that rehabilitation of a client to maximum potential requires individualized solutions and mobility is no exception.

One mobility solution for some severely disabled individuals is use of a personal licensed vehicle. It is the intent of this presentation to review some of the elements of a delivery system which could be used to help a client become an independent driver.

I. The Delivery System

Accountability in any delivery system requires that both the deliverer, the receiver and the contractor for the service clearly understand the goals expected to be attained, the methods to be used to attain the goals and the criteria to be used to evaluate and modify the service system. In this system, the client must be Identified, Assessed, Trained, Evaluated, Licensed. The process requires a TEAM approach. Members of the team are the primary health service group (physicians, nurses, therapists, counselors) and the facilitators of the training program (members of the training agency, the licensing agency, and the engineering agency).

A. Identification

Those involved in the primary rehabilitative service to the disabled client are usually among the first to consider the client's driving potential. There are, however, few references to assist them in the judgments which relate functional ability to driver performance. One reference is the Driver Licensing Guidelines for Medical Advisory Boards[2] developed by the American Medical Association in conjunction with the American Association of Motor Vehicle Administrators. These guidelines are meant to be interpreted in view of individual difference except where driving is contra indicated. They are not an end in themselves. Other resources include professionals trained to teach disabled drivers, the licensing agency and the Medical Advisory Board of the licensing agency.

Recommendations for driver assessment are generally based on personal driving experience and knowledge of available equipment. Patients are often denied the opportunity for independent mobility because the service group lacks knowledge about current assessment techniques and modern adaptive equipment. Even if there is doubt about the patient's ability to drive, an opportunity for assessment should be provided. To deny the opportunity, for whatever reason, (including embarrassment to the referring staff) may be to deny the opportunity for independent mobility.

B. Assessment

Criteria related to successful driver performance, whether able bodied or disabled, remain unidentified at this time. Research in this area

is ongoing. However, subjective judgments remain a part of the assessment process. As in the practice of the art of medicine, clinical experience in the process is essential--judgments become refined. Space age technology and the civil rights movement have both strongly influenced attitudes toward assessment. Engineering capability has the potential to interface the most severely disabled with automotive vehicles. However, the limits of functional ability which can survive the dynamics of the highway environment are not clearly defined. Can the disabled driver handle a skid, an evasive maneuver such as a fast lane change, etc. Are these performances expected of other licensed drivers and, if not, would it be discriminatory to require them of the disabled?

Assessment at best holds risk. Therefore, it is essential to reduce the level of risk by accumulating medical history currently believed to influence safe driver performance. Driving is a perceptual-judgmental-motor skill. It is an integrated complex process with limited scientific understanding. There are no known pre-driving tests which clearly define driving potential. Consequently, driver assessment remains elusive.

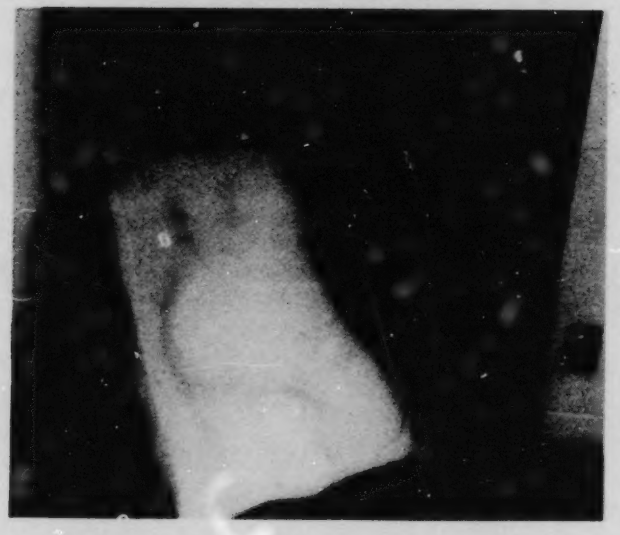
1. Medical History. Assessment should be based on information related to motor, visual, psychological, communication and neurological problems. Behaviors associated with these systems may range from subtle to severe and stress, as in driving, may produce bizzare effects. Generally, neurological impairment represents the highest level of risk for driving and orthopedic impairment the lowest. Information related to prognosis, stage of rehabilitation, medication, fatigue, frustration tolerance, personal risk assessment, body scheme, involuntary body movements, dominance, trunk stability, auditory and visual perception, sensory loss, compensatory training capability, etc., represent some of the elements critical to instructional design and management.

2. Adaptive Equipment. Functional ability related to driving skill has clearly defined parameters. Designing an adaptive driving system to accommodate functional ability is limited only by engineering creativity. (Cost not considered.) Adaptive equipment may range from a simple steering knob to a unilever control for accelerating, braking and steering. This may be actuated by either an upper or lower extremity. Perhaps even the head or mouth! Accessories may be actuated by movement of any portion of the body. This should not interfere with the simultaneous manipulation of basic controls in a dynamic setting. Fig. 1 illustrates the most severely disabled driver known to be licensed. This quadruple amputee was fitted with many unique devices--a prosthetic arm attached to a left hand control, a cup for steering with her right stump, a head control device for signaling and a microswitch behind her head for the horn. A specially made push button switch panel operates all other accessories. Information about the equipment is available from her instructor, Harold F. Risk.

Fig. 1 Quadruple Amputee

a. Positioning. Modification of the driving seat is often required to accommodate the disabled driver. Impact resistance and safety may be altered as a result of the modification. Driving from a wheelchair, for example, has many inherent problems from a safety point of view. The chair and tie down systems are both a concern. It is not recommended to drive from a wheelchair if a transfer is at all possible.

One solution to a seating problem is illustrated in Fig. 2a and 2b. This polyform seat was customized for a driver with limited hip flexion. It provides good support and stability in a dynamic setting which could not be provided with cushions. It was designed at the Job Development Laboratory of George Washington University, Washington, D.C. It should be noted that the seat has multiple uses at work and at home.



b. Mechanical Controls. Simple hand controls have changed little since their invention. (A recent survey indicates that users would like them to be stylized--perhaps matching car interiors.) Three principles of hand control movement are available (1) push/pull, (2) push/twist and (3) push right angle downward. The push displacement engages the brakes in all three types and the alternate movement engages the throttle. Hand controls are recommended according to functional ability and may be either left or right handed.[5]

c. Servo Controls. When the disabled driver's range of motion and applied force do not match conventional hand controls, alternatives are available. Each of the hand operated systems illustrated employs reduced effort for steering and braking. Both maneuvers require limited displacement. Engineering details, costs, and forces required to operate the systems may be obtained from the manufacturers. All systems are production items.

Scott Van[6] - Fig. 3 This system can be operated by one hand or foot as functionally required. Pushing the miniwheel forward accelerates the vehicle and pulling backward brakes it. Steering is accomplished by a 90° displacement of the wheel in the chosen direction of travel. The push button system controls all other functions of vehicle operation. The conventional accelerator and brake are retained for able bodied use.

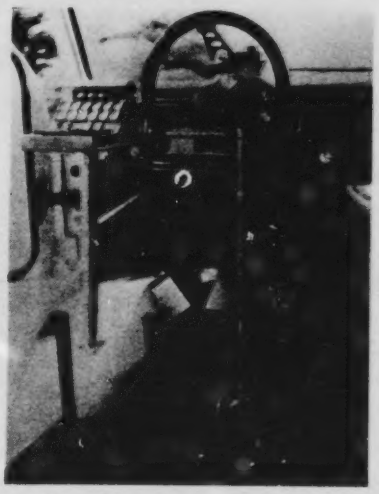


Fig. 3

CCI-Hardin[7] - Fig. 4 The unit mounted near the driver's armrest has a handle which controls accelerating and braking. Ideally it can be positioned where functionally required. Pushing forward engages the accelerator and pulling backward engages the brake. Steering is traditional. This system does not interfere with normal operation of the vehicle.

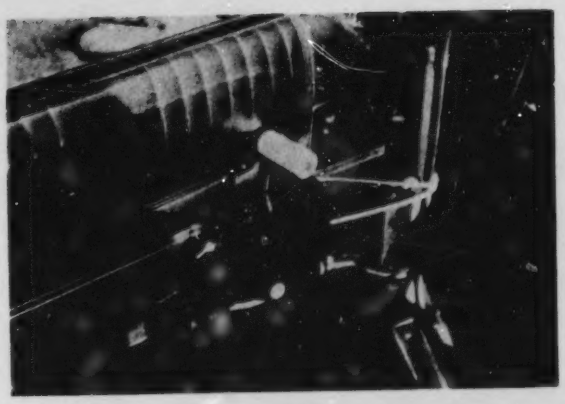


Fig. 4

Target Van[8] - Fig. 5 The conventional driving controls have been removed in order to accommodate this system. Steering, accelerating, and braking are accomplished through a horizontal plane. They can be customized as required. Adducting the left arm engages the accelerator. All other controls are operated by toggle switches. Restricted use of the vehicle is recommended to those trained on it.

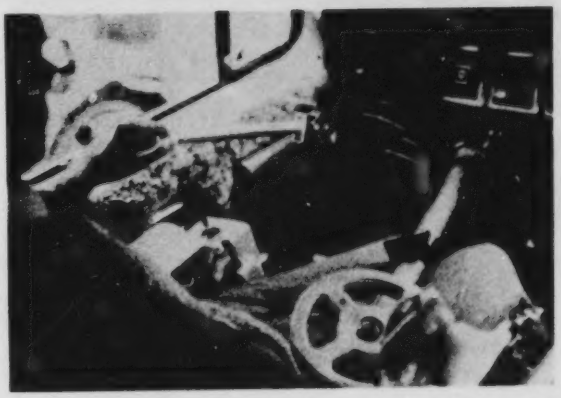


Fig. 5

d. Foot Controls. System Franz[9] - Fig. 6 This system was designed for armless drivers. The pedal is attached to the steering column through a gear and chain mechanism. Steering is accomplished by rotating the pedal like a bicycle pedal through a 360° path. When the rotation begins with a forward movement, the vehicle turns right. Rotating backward turns it left. Accelerating and braking are accomplished in a conventional manner. Accessories have been modified for foot operation. The vehicle can be driven in a traditional manner when the pedal has been removed.

Fig. 6

C. Training

Entry level competencies and terminal goals influence instructional management. Previously licensed, traumatically injured drivers require different approaches than congenitally disabled non drivers. There is an identified hierarchy of skills required to accomplish the tasks of driving. It is logical that experiences be structured to match individual abilities within this hierarchy. The number of lessons required varies with the individual and level of competency to be developed. It should be remembered that training programs vary with the educational philosophy of the instructor. Therefore, when contracting for driver training service, it is important to define the terminal goals. What levels of competency are to be attained--acquistion, proficiency or maintenance? Will the service train the client "to the licensing exam" or train "to performance levels which include evasive maneuvers and skid control"? These are not necessarily the same. Licensing in some states requires minimal performance.

Liability related to driving is causing licensing agencies and training centers to critically review the quality of their service. Recent litigation in two states has challenged the licensing process of disabled drivers. This should not reduce our involvement as advocates of independent mobility. Rather it should cause us to want to improve the quality of our service.

Some training programs use simulators and driving ranges. Knowing when not to use either phase is as important as knowing how and when to use them. One of the factors in favor of their use is the protected environment they both provide for habit pattern training. Disabled licensed drivers function on internal computers which no longer provide reliable feedback. New patterns of behavior which are reliable in emergency situations must be learned. Showing a client how a hand control functions and providing two hours of practice does not meet competency criteria. Simulators can provide additional experience.

Throughout training questions are constantly being asked about driver performance. What behaviors reveal consistently dangerous driving? Can they be corrected or can compensating actions be taught? What is an acceptable level of risk? Are risk perception and response skill coordinated?

The pitfalls of training may be numerous, but the rewards of successful training outnumber them.

D. Evaluation

Assessment is the process of determining a client's ability to attain independent mobility by means of a personal licensed vehicle. Evaluation differs from assessment in that it is a process which is structured to review the delivery system.

Instruments designed to evaluate the system should critique the assessment process and the training program. Did the individual attain the goals of the program in the anticipated time? Was failure appropriate? If not, was it related to administrative procedures, scheduling, absenteeism, inadequate assessment, inappropriate or inadequate match of adaptive equipment, lack of clarification of intended goals, etc.? Do administrative constraints allow for modifications in the identified problem areas? How would recommended changes influence cost of delivery? Does the contractor support the changes? The evaluative process should generate change in the delivery system which result in greater efficiency, economy and effectives.

E. Licensing

The state driver licensing agency determines the qualifications for driver licensing. The liability related to licensing rests with this agency and not the training agency.

Although the criteria for licensing varies among states, each state has a specific process for licensing. It is essential to operate within the framework of this process. Rehabilitation of previous licensed drivers provides an example. Some states allow a disabled individual to be rehabilitated on a license considered valid at the time the disability occurred without notification to the state. The licensing agency must be notified of the change in the client's physical status only when renewal is required. Other states require drivers who are being rehabilitated to begin the process anew by obtaining a learner's permit. Some states require no permit if the disabled individual is being trained in a state certified driver training program.

Driver licensing examiners often receive in-service training related to disabled drivers. A review manual to aid examiners in recognizing signs and symptoms of medical conditions that may limit safe driving ability has been prepared by the U.S. Department of Transportation.[10] This manual used in conjunction with a coordinated series of films has the potential for reducing licensing discrimination for the disabled.

Since advanced technology can accommodate more severely disabled drivers, concerns in the licensing process are changing. Discrimination toward the disabled is no longer a major issue. Concerns have shifted to an identification of the limits of disability beyond which it is unsafe to drive. Performance criteria related to safe driving must be identified for all drivers regardless of ability.

II. Summary

The delivery system which assists the disabled individual to attain the goal of independent mobility through a personal licensed vehicle requires an interagency/interdisciplinary approach. Assessment for driving should be initiated by a clinical team trained to relate physical and psychological functional ability to the tasks of driving. Training should be structured on an individualized basis.

Adaptive equipment which maximizes safe performance should be recommended Superfluous equipment should be avoided. As training progresses and/or the client's condition changes, it may be advisable to alter equipment, i.e., remove or add. Individualized instruction should be designed to attain program goals. Psychological factors associated with the rehabilitative process may influence individual progress. Temporary termination of training should be considered if routine progress is not made.

Evaluation of the system should improve delivery procedures. Emphasis should be placed on those candidates not successfully completing the program for whatever reason. Identification of alternative procedures should result in greater efficiency. Finally the licensing process should be reviewed for uniformity and performance criteria. As technology advances, it becomes critical to identify the level of impairment beyond which it is unsafe to drive.

There is a genuine need for standards to be developed for assessment and adaptive equipment. The concept of regional mobility centers emphasized at the interagency workshop on Personal Licensed Vehicles for the Disabled in 1976[11] should be implemented. A proven systematic approach matching a particular disabled individual to an optimum combination of components and then training that individual for safe performance in the highway environment is critically needed.

References

[1]The Congress of the United States, Congressional Budget Office, Urban Transportation for Handicapped Persons: Alternative Federal Approaches #1979-0-53-360 U.S. Government Printing Office, Washington, D.C., 1979.

[2]The American Association of Motor Vehicle Administrators, Driver Licensing Guidelines for Medical Advisory Boards, (Washington, D.C., 1980.)

[3]Harold F. Risk, "Driving Control and Equipment for a Quadruple Amputee Patient," Archives of Physical Medicine and Rehabilitation, Vol. 61 (1980), 48-49.

[4]Harold F. Risk, Traffic Safety Center, St. Cloud State University, St. Cloud, MN 56301.

[5]Human Resources Center, Hand Controls and Assistive Devices for the Physically Disabled Driver (Albertson, New York, 1977.)

[6]Mobility Engineering and Development, Inc., 7131 Hayvenhurst Avenue, Van Nuys, CA 91406.

[7]Creative Controls, Inc., P.O. Box 412, Birmingham, MI 48012.

[8]Target Industries, Inc., 1264 Union Street, West Springfield, MA 01089.

[9]Die-a-matic, Inc., 4004 Fifth Road, North, Arlington, VA 22203.

[10]U.S. Department of Transportation, National Highway Traffic Safety Administration, Traffic Safety Programs, Screening for Driver Limitations, Washington, D.C., 1978.

[11]Rehabilitation Engineering Center, Moss Rehabilitation Hospital, Personal Licensed Vehicles for the Disabled, Philadelphia, PA, 1976.

Bibliography

American Automobile Association. The Handicapped Driver's Mobility Guide, #377, Falls Church, VA, 1978.

U.S. Department of Transportation, National Highway Traffic Safety Administration, Traffic Safety Programs. The Role of Medical Advisory Boards in Driver Licensing, Washington, D.C., 1977.

CONCEALABLE HELMET FOR SEIZURE-PRONE INDIVIDUALS

by

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I. The Problem:

In 1976 the staff of the Job Development Laboratory began a research project entitled, "Technical Support Services to the Developmentally Disabled in Region III," by surveying Region III facilities on their specific technical support needs. Their responses indicated that one of the most common problems was the need for suitable head protection for persons suffering seizures or with self-abusive behavior.

Investigation into available sports equipment revealed a new product -- the Cooper SK-600 hockey helmet -- which was well suited to meet these needs. Washable, well-balanced, and providing full protection to the head, it also has a hinged face shield which makes feeding easier than with conventional fixed-shield helmets. This Cooper helmet is now commonly used in institutions.

In spite of its benefits, however, this hockey helmet still has the drawback of being quite conspicuous. For non-institutionalized, seizure-prone persons, appearance is a major consideration. Many choose to risk head injury rather than wear an attention-drawing sports helmet. Many, therefore, bear scars of repeated injuries from falling. Since no cosmetically acceptable helmet was available, the Laboratory set out to develop a thin, light weight helmet which could be concealed beneath a cap, wig, or other inconspicuous headgear. The design was intended to alleviate the following problems common to conventional protective headgear:

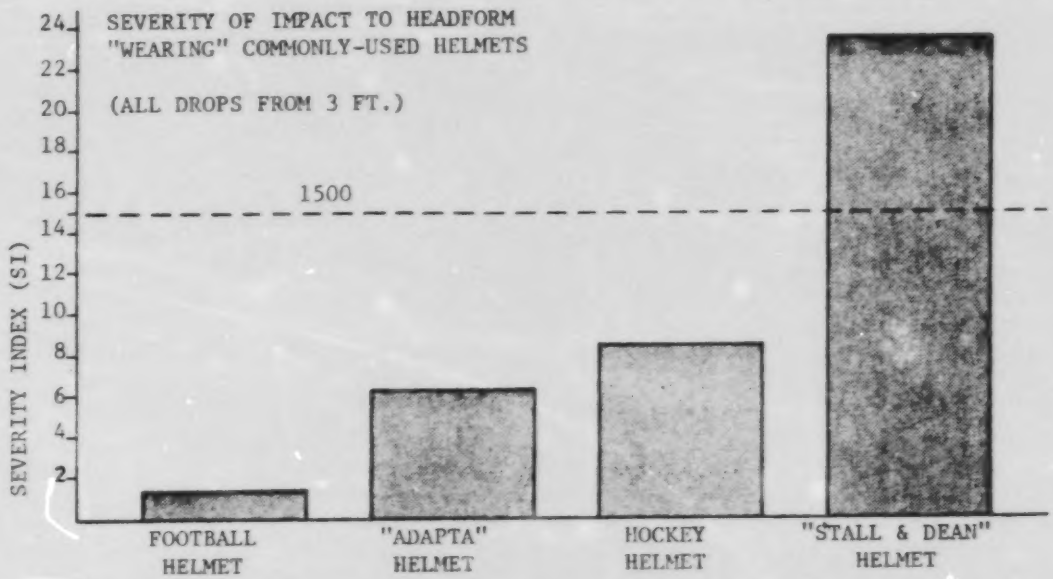
- Excessive weight compounding balance and fatigue problems
- Excessive size and unnatural appearance
- Poor ventilation
- Poor fit, especially for children or persons with abnormally shaped heads
- Difficulty keeping helmet clean

II. Process

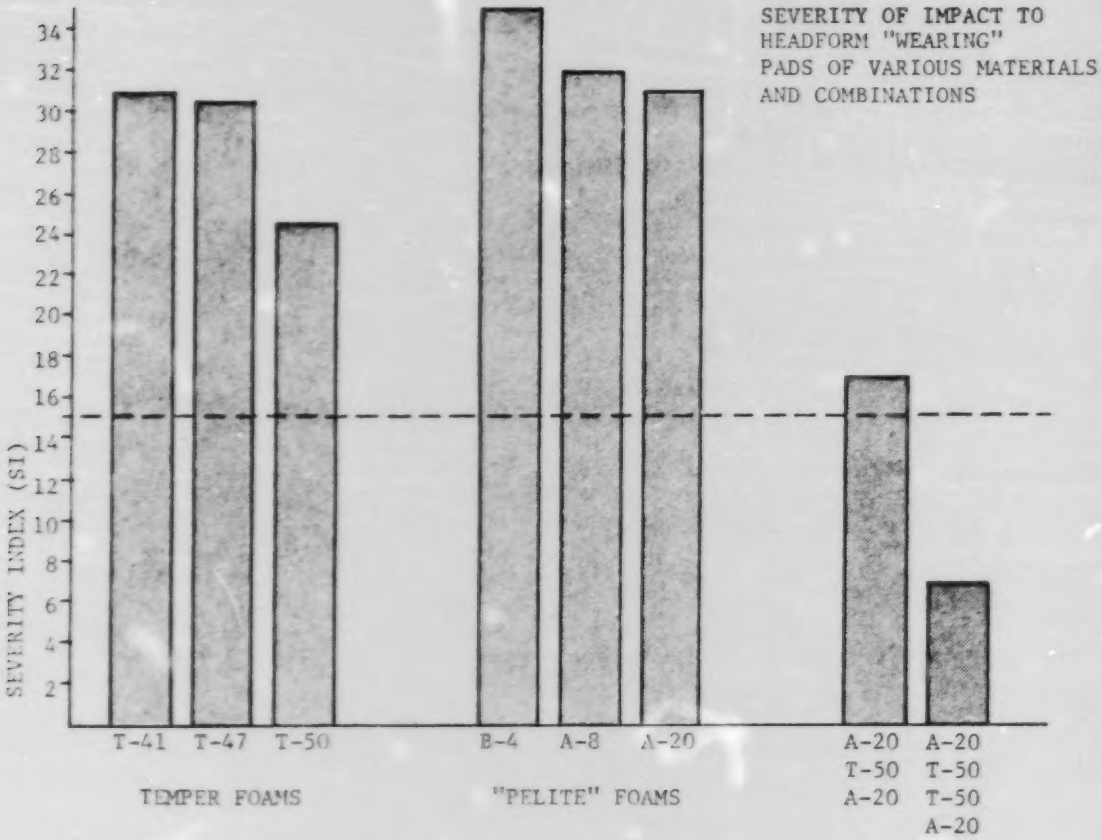
The first step in developing the new helmet was to find a suitable material which could provide adequate protection from head injuries. At the National Bureau of Standards' Product Safety Technology Division, Mr. R. Berger and Mr. N. Calvano conducted a study comparing helmets which were commonly used

in institutions. The Severity Index (SI), a measurement of human tolerance to cerebral concussion, was computed by dropping an instrumented headform "wearing" each helmet onto a floor pad from a constant height, as shown:

Although an SI of 1500 is considered the limit of tolerance above which concussion is likely, the Index is best used as a comparative, rather than absolute, measure of a device's protective qualities, since so many other factors (type of fall, surface of impact, etc.) may contribute to the severity of head injury. Following are the results of the initial testing:



The Laboratory staff then began experimenting with various materials having the qualities of light weight and high shock absorption. The most appropriate materials seemed to be Temper Foam or T-Foam (manufactured by Edmont-Wilson, Coshocton, Ohio 43812, 614/622-4311, Attn. Bruce Larson) and Pelite high density polyethylene foam (distributor: Pel Supply Co., 4472 West 160th Street, Cleveland, Ohio 44135). T-Foam, a NASA-developed, resin impregnated foam, has excellent shock absorption but is relatively sensitive to moisture and chafing. Pelite polyethylene foam, on the other hand, is well suited for long term skin contact and is often used as a socket liner in light weight prostheses. A logical combination, then, seemed to be to sandwich T-Foam within layers of Pelite polyethylene foam. Various densities of these Pelite/T-Foam/Pelite "sandwiches" were then compared with the following results:



As may be readily seen, the A-20/double T-50/A-20 pad performed nearly as well as the ADAPTA helmet (see figure 1) which is .75 inches thick. This effective "sandwich," however, was still very thick (about .70 inches) and did not meet the specific need for which it was intended, namely, to be unobtrusively concealed beneath common headgear. The Laboratory staff, therefore, decided to proceed with the thinner, single T-Foam "sandwich"

(about .50 inches), perhaps applying a double T-Foam pad where maximum protection of specific areas was essential.

Having arrived at a "sandwich" using ¼" T-50 T-Foam within inner and outer layers of ¼" A-20 Pelite polyethylene foam, the Laboratory began to examine fabrication techniques. Since good fit is essential to appearance and protection, each helmet was vacuum-formed on an individually made plaster headform for perfect, custom fit. After preparing the plaster head casting, several 3/8" rubber strips were added to the form to provide ventilation tunnels in the finished helmet. The Pelite inner liner of the helmet was then vacuum-formed over the head-form and rubber strips and trimmed to the hair line. Pads of T-Foam were then glued to the inner Pelite liner between the ventilation tunnels. The outer layer of Pelite was vacuum-formed over the other built-up layers, trimmed to the hair line, and all edges were contact-cemented. Finally, the top section was removed for ventilation and this edge was also contact-cemented. The completed helmet was about .50" thick and weighed about 2 ounces, as compared to the ADAPTA helmet which is approximately .75" thick and weighs 14 ounces. The fabrication process is illustrated in detail below.

(1) Using plaster bandages, a mold is made of the subject's head which is protected with a bathing cap. A plaster form is made from the mold and ventilation tunnels are added to provide cooling.

(2) The plaster form is covered with two ordinary stocking caps to provide a comfortable fit in the final helmet. Using ¼" Pelite, a liner is vacuum-formed over the form with the ventilation tunnels and stocking cap covering. The Pelite liner is then trimmed to the hair line.

(3) ¼" T-Foam pads are glued in place over the liner.

(4) A final outer liner is vacuum-formed over the form to seal the "sandwich."

III. Results

In the Fall of 1977, information on the Laboratory's newly developed helmet was published in the project's newsletter, Response, in the Epilepsy Foundation of America's newsletter, Spokesman, and was later cited in several other publications such as the Physical Therapy Journal. This publicity prompted a deluge of interest from across the country. In selecting persons to test the helmet, however, the Laboratory was limited by funding restrictions and practical considerations of the custom process to working locally with residents of Region III.

Three Region III residents, all of whom had refused to wear conventional helmets despite repeated head injuries due to falling, were offered an opportunity to test the helmet — all accepted. The three subjects were provided with custom-formed helmets; two wore the helmets under wigs, and the third fitted his helmet into a golf cap. After more than six months of use, the results have been very promising. None of these subjects has suffered head injury while wearing the helmet, although all have had seizures, many of which occurred in potentially hazardous areas such as on concrete steps. As the counselor of one subject described:

> "Her fall was backward onto lockers in the shop. Her body became rigid and fell with dead weight directly on the back of her head and shoulders. Her head struck the edge of the metal locker. When we took off the wig with the device we anticipated with the force of the fall and the way her head hit on the metal corner to find a laceration. We found her scalp to be only slightly red, with no apparent thrombosis and no apparent concussion."

As an additional benefit, two of the subjects experienced a marked decrease in the frequency of seizures while wearing the helmet. Neurologists have noted a direct relationship between reduced anxiety and frequency of seizures. In these cases, reduced anxiety may be attributed to the wearer's confidence in the effectiveness of the helmet.

Several problems with the helmet remained. Since concern with appearance precluded the use of straps, securement of the helmet was a problem. The golf cap fit snugly enough to avoid the problem, but the subjects wearing wigs found that Velcro or loose stitching was required to secure the helmet inside a snug-fitting wig.

Ventilation remains a problem with the helmet in its present design. One solution is to abandon the complete helmet and use instead small sections of protective pads on areas requiring head protection. These pads could also be secured with Velcro or loose stitching into a cap or wig. This minimizes total enclosure of the head while maximizing air spaces. The Laboratory has fabricated curved sections of Pelite/T-Foam/Pelite "sandwiches" of about 1½" by 4½" which seem very promising for widespread use. Since the need for custom fitting is eliminated, a larger population could be served. Fabrication time and costs are also reduced. The Laboratory staff feels that this concept would be a valid departure for future research.

IV. Summary

The Job Development Laboratory's concealable helmet for head protection is, admittedly, a compromise of many factors. It is certainly possible to construct a helmet which provides more protection. It can also be argued that, in view of National Bureau of Standards test results, double layers of T-Foam should be the minimum thickness allowed in fabricating the helmet. We agree that padding should be as generous as cosmetic concerns allow; unfortunately the double T-Foam helmet was cosmetically unacceptable. Persons concerned with appearance who refuse to wear commercial helmets should be offered an alternative which is lighter, thinner, and less conspicuous than available products. The Laboratory staff feels that the Pelite/T-Foam helmet, though less effective than commercially available models, is an acceptable alternative -- it provides at least some protection for persons who otherwise receive no protection from head injury due to falling. Further research with a larger population is necessary to verify these results.

References

Claus, W.D., Jr. Bioengineering Considerations in the Design of Protective Headgear. New York: The American Society of Mechanical Engineers, 1976.

"Concealed Head Protection." Response, 2 (December 1977).

Hodgson, Voigt R. "National Operating Committee on Standards for Athletic Equipment Football Helmet Certification Program." Medicine and Science in Sports, 7 (1975), 225-232.

"New Head Protection Device." American Physical Therapy Journal, 58 (August 1978).

"Research Staff Design New Head Protection Device." National Spokesman, 11 (March 1978), 9.

"Unobtrusive Protective Headgear." Epilepsy International News (April, 1979), 8-9.

10.

SUPPORT AND REHABILITATION SERVICES FOR SEVERELY ORTHOPEDICALLY DISABLED COLLEGE STUDENTS

by

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The provision of support and rehabilitation services for severely orthopedically disabled college students is a recent development in American higher education. Concern and compassion for disabled persons has long been a verbalized ideal in American society and it is interesting to note that higher education is among the last social institutions to activate verbal idealism into programmatic reality. At long last our nation has come to realize that it cannot afford to waste the tremendous human potential of disabled persons so long encapsulated by fear, myth and misunderstanding.

St. Andrews Presbyterian College opened on a new eight hundred acre campus in 1961. During the planning period in the late 1950's, the Board of Trustees sought a new and innovative curriculum, a creative student personnel program and avenues of unique service to society. A program of service to disabled students was envisioned and the campus design embraced the concept of a barrier free environment.

A formal program of support services was begun in 1964 in the form of providing training for roommates of disabled students. This was followed by an indepth study of the psychological effects of such a social interaction on the individuals involved. In the following years, the college has expanded support and rehabilitation services at a gradual rate influenced by the availability of knowledge, personnel and finances.

The present program serves forty-two orthopedically disabled students, of whom twenty four are disabled at the quadreplegic level. The program is is based in The Burris Rehabilitation Center located in the residence hall area of the campus, and employs twenty-nine full and part-time staff members. It must be noted that visually and hearing impaired students are also served, however that program is not described here.

The St. Andrews program involves sixteen service areas which are essentially provided to currently enrolled students and three service areas which are provided to both the current students and graduates. The Services to currently enrolled students include: (1) Medical Services, (2) Student Aides and/or Attendant Care, (3) Adapted Physical Education, (4) Physical Therapy, (5) Adapted/Special Transportation, (6) Adapted Recreational Programs/Facilities, (7) Wheelchair/Appliance Repair, (8) Secretarial Services, (9) Academic

Aides, (10) Food Service Aides, (11) Faculty Consultation, (12) Individualized Services, (13) Improvement of the Barrier Free Environment, (14) Reserved Parking Facilities, (15) Cooperation with State Vocational Rehabilitation Agencies, (16) Consultations.

In addition, three program areas involving both current students and graduates include: (1) Adaptive Housing Training/Experience, (2) Adapted Driver Education, (3) Career Counseling and Placement Services.

Experience at St. Andrews indicates that disabled students achieve academically as well as non disabled students, contribute significantly to the campus community and that non disabled students feel their total college experience has been enriched by their interaction with disabled students.

It is imperative for the future of our nation that institutions of higher education and rehabilitation professionals cooperate to insure a positive learning experience for every academically qualified person regardless of physiological disability.

SMALL STEPS ON AN UNPAVED PATH
(Malcontents Biting the Hand that Feeds)

by

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As is readily evident from the title, this paper is about a group home for mentally retarded adults. The group home serves twelve people, about half of which are also physically disabled. The house is located in Vienna, Virginia, and was opened in July, 1979. The group home was a joint effort of the Fairfax-Falls Church Community Services Board, Fairfax County Redevelopment Authority, and the Virginia Housing Development Authority.

To end the paper here would leave the impression of a rather non-descript event. Depending on one's point of view, the opening of this group home can be seen either as a giant step forward or another waste of the tax-payers money. As usual, the truth lies somewhere inbetween.

The remainder of this paper will deal with some of my thoughts as I trace the history of the home, what its location, design and size tell us about the current state of residential planning. Finally, I will posit that this home is not an exception, but part of a pattern that will likely be repeated largely because of an antiquated headset, compounded by the perennial "chasing the bucks" that human services administrators do so well.

I became Director of Community Residences in November, 1978. Plans were well underway to construct the group home. I was told that it was a group home for non-ambulatory adults. Sure, I had seen people in wheelchairs before. After all, I worked in a state institution for the mentally retarded. But now, the issue was community living.

Being a parambulatory normate, issues regarding physical access to community amenities for those physically disabled people were foreign to me. Past rememberances dominated my thoughts; one time I actually saw someone in a wheelchair using a handicapped parking space; wheelchairs doing "wheelies" to get over "high lipped" curbs, and a vivid memory of a man in a wheelchair in the bathroom of a sports arena. There was no special facilities for wheelchairs. He had to use the regular urinal, he wet all over himself. That one got to me. I kept thinking, "God how embarrassing."

These fleeting exposures were the main extent of my experience with physically disabled people. Now suddenly, I was to open a twelve bed facility constructed specifically for physically disabled people.

I read everything I could on Barrier-Free design, and physical handicaps. I maintained frequent contact with the Housing Authority and the local institution that hoped to place some of its clients in the home. I was struck by the incredible amount of planning that went into the construction of the building. This was in almost complete contrast to the lack of understanding and planning for meeting the clients needs after the building was completed.

More and more I realized that a common pattern was emerging. The Housing Authority had never been involved in a project of this type before; they viewed this project in much the same way as their other housing projects. This coupled with the architect's requirements (carpeting 18 inches up the wall to prevent wheelchair marks on the wall, individual mailboxes complete with keys, and the door locks being too high for someone in a wheelchair to use) all contributed to making the place more like a mini-institution rather than a home. Fortunately all of these original designs were eliminated or modified. Many other features were unchangeable, all having varying degrees of impact on creating a home-like environment.

The home finally opened four months behind schedule. It was just as well, because there was more time to screen potential clients, hire and train staff and purchase furniture and supplies. The home was dedicated by the Lieutenant Governor with many local politicians and dignitaries in attendance. The opening was proclaimed as a great step forward in care and treatment of mentally retarded.

It wasn't until several months later that some of the shortcomings became readily apparent to both staff and clients. A major drawback was the location of the home. Situated on a dead end road, there were no houses nearby. Located next to a church, up the street was a school for special education, and a fire station. The Housing Authority assured us that in the next few years more houses would be built, since the home was surrounded by county owned land.

There were many features inside the home that ranged from inconvenient to inexplicable. While there were no cabinets under the sink, the drain pipe was still in the way. The washer controls were on the front, but the dryer controls on top. At the entrance to the living room and family room there are sliding glass doors. This was a nice touch, but the doors slide along tracks that protrude from the floor, making it difficult for wheelchairs to traverse the barrier.

Do I protest too much? Are the criticisms too harsh? I think not. Certainly this home is better than an institution. Some features in the architecture are well done and even very attractive. My concern is that too often in human services we say "we'll do better next time" or "we did the best we could". This belief only gives further credence to the continued view that we are basically a charity organization and as such should be thankful for what we've got.

With shrinking funding sources, and increased accountability, the future is limited. Would I seek funding for another twelve bed Barrier-Free home? Probably not. I think twelve is too large a number. The staff and clients at the home agree.

Finally, there are five major points I would like to make regarding the development of community living arrangements for physically disabled people:

1. Attitudes of protection and separation of handicapped people will continue to dominate architecture and residential planning.

2. In the rush to create residential alternatives for physically disabled people, programs will continue "chasing the bucks", namely devising programs around available funding. This could very well lead to ghettos of specially adapted apartment complexes and group homes both unduly large and non-integrated.

3. Future funding sources will be mostly governmental. Limited funds will contribute to larger facilities, citing economy of scale, efficiency and other wrong but justifiable reasons as a basis for funding and program bias.

4. It is possible and certainly normative to create small residences that serve ambulatory and non-ambulatory clients. These residences can be in regular neighborhoods, with a barrier-free design that is both practical and inconspicuous.

5. Much of the fault for the current ignorance, bias, and misinformation about the needs and potential of physically disabled people rests with residential programs themselves. Precious little energy has been spent in education efforts that could increase support and acceptance of community residential programs for physically disabled people.

The next decade will continue to present hard choices to human services administrators, especially with regards to housing for handicapped people. We must have a clearly defined strategy for meeting this need, realizing that funding lies woefully behind plans. But perhaps the biggest temptation will be to increasingly compromise principles and plans in order to assure funding. Each administrator will have to decide the cost-benefit each time he/she compromises regarding location, size or function of a residence.

Our decisions impact us, but most directly the lives of those who will live in the residences. The real litmus test for the administrator is, "Would I want to live there?"

SECTION III

MEDICAL AND COMMUNICATION INTERVENTION

MOUTHGUARD FOR DROOLING CONTROL

by

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The purpose of this paper is to describe the use of an appliance to control drooling in a cerebral palsied patient.

When first seen, the patient was twelve years of age. The case history indicated a diagnosis of cerebral palsy at an early age.

Clinical examination revealed an anterior dental open-bite and anterior tongue-thrust (reverse swallowing). Thumb-sucking was also present. The patient drooled continuously and seemed unaware of the excess saliva. There was no attempt made reflexly to swallow although the patient was able to swallow when reminded to do so. Ritalin, 10 mg./day was being taken.

After discussing the problem with the patient and his mother and determining that both were very anxious to stop the drooling, an appliance was constructed according to the method described by Jerry R. Green.[1] The appliance was placed. It was worn ten minutes per day for one week to determine if it fit correctly and that there were no sore spots. Once the appliance was corrected, the patient was instructed to wear the appliance at night. He was also told that it might fall out initially and not to let that discourage him. It took two weeks before he was able to keep it in all night. His mother indicated that the pillow was no longer soaked in the morning, and a persistent rash on his cheeks disappeared. Thumb sucking also stopped at night.

At this point, the patient had sufficient confidence in his ability to manage the appliance to wear it during the day; first alone and then at school. A second appliance was made to be kept at school. The teacher was made aware of his use of the appliance and the fact that he would be unable to talk with it in. This minimized the chances of embarrassment occurring.

After one year, the patient's mother indicates that the appliance is now used at night and that drooling, thumb-sucking and mouth-breathing are well controlled. A soft collar is also being used to aid in controlling head position. The medical used, Ritalin, has been switched to Dexidrine to aid in reducing salivation.

In summary, an appliance has been described which aids in the control of salivation in the cerebral palsied. It is hypothesized that the action of the appliance involves a "pooling" of saliva which results in the

triggering of the swallowing reflex. The presence of the appliance also necessitates the need for increased lip tension to keep it in. This strengthens the peri-oral musculature and aids in the correction of mouth-breathing and tongue-thrust.

Perhaps the greatest benefit is to the self-image of the patient who has been given a tool to help overcome a problem which is a social stigma allowing him to function more normally in a social setting.

Appliance Fabrication:

The appliance is constructed by several different commercial dental laboratories from plaster models of the dentition. It is not necessary for an orthodontist to take impressions and fit the appliance. Impressions can be taken by a general dentist, at a dental school or, depending on state dental laws, by a hygienist or assistant. A wax bite is taken of the occlusal surfaces of the upper and lower teeth in what is called centric relation. Plaster molds of the upper and lower impressions are poured up and these casts plus the wax bite are sent to the lab with a prescription for a "positioner." It is possible to have holes drilled in the positioner to allow some air to pass through in the event that the patient has difficulty in breathing through the nose.

The appliance is available in black, pink or white rubber, or clear plastic. The latter is probably the least conspicuous and most comfortable, although replacement will probably be necessary as the plastic will break down in one to two years. Provided that no changes occur in the dentition, a new appliance can be constructed from the initial models.

Additional information and a reprint of the original report are available from the Cerebral Palsy Research Foundation of Kansas, Inc., 4320 East Kellogg, Wichita, Kansas 67218 (316/683-5627).

Footnotes

[1]Jerry R. Green, "Appliance to Control Drooling in Cerebral Palsied Clients and Others Who Lack Control of Saliva Due to Accident or Trauma," Proceedings: Fifth Annual Conference on Systems and Devices for the Disabled, Baylor College of Medicine, Texas Institute for Rehabilitation and Research, June 7, 8, 9, 1978, Houston, Texas, pp. 192-95.

PROTECTIVE AIDS

by

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Protective aids are designed to protect physical injury to children with developmental disabilities. Most aids are designed to protect the head, limbs, or skin. Some are designed to restrain or secure the child from falling. The design and the material used for protective aids have constantly been improved over recent years. The availability has also improved so much that most of the aids are now readily available through commercial surgical supply houses. Special designs and individualized models are still fabricated by occupational therapists.

I. Nature and Type of Injuries

Children with developmental disabilities are characterized by various degrees of intellectual dysfunction and physical disability. They have serious deficiency in judgement and motor planning which lead to frequent injuries occurring in the following circumstances:

A. Falls

Falling is common in children and is even more common in developmentally disabled children. Head injury accounts for half of the accidental injuries requiring hospitalization.[1,2] Head injury frequently adds insult to the already impaired function in the central nervous system. Head injury also may have some serious effects during a period when the central nervous system is still developing and maturing.

Falling is easier to prevent when the child is small, bed-confined, or wheelchair confined. The child can simply be placed in a bed with protective pads and rails or secured onto the chair. When the child becomes ambulatory, the risk of falling becomes greater. The child cannot be trusted to observe safety precautions. In the case at higher risk of falling, a helmut is provided. Protection of other parts of the body during a fall are either impractical or inefficient and are not commonly used.

B. Injuries to the Extremities

Because of organic brain impairment, a seemingly purposeless, repetitive hitting of the extremities is frequently observed, e.g. hitting the face with the hand, battering the table with the hand, kicking the bed with the leg, chewing the fingers and biting, etc. Various degrees of injuries

can result from this repetitive trauma. Restraining with a limb holder and use of a padded mitten have been applied to minimize the injury.

The hyperactive child is destructive. During the destructive activity, there may be infliction of injury to himself. Choreoathetoid type of involuntary movement may also cause injury to the involved extremities.

C. Skin Injury

The development of decubitus ulcers in children with developmental disabilities is not as common as adults with spinal cord injury or adults with debilitative illness. Decubitus ulcers, however, occur frequently in spina bifida or in other conditions which may result in anesthesia of the skin.

In developmentally disabled children, ulcers are frequently observed in bony prominences or at skin surfaces covering the joints. Children with nutritional problems or with atrophic muscles have prominent joints and bony contours. These areas are easier to subject to chronic and repetitive trauma and may finally ulcerate.

Spastic paralysis and rigid extremities are often associated with deformities and contracture of the joints. The deforming force also stretches the skin and predisposes the overstretched skin at the prominent area to injury. These predisposed areas of skin can frequently be protected by the use of appropriate padding or cushioning.

D. Seizure Disorders

Grand mal seizure is characterized by tonic and clonic alternating movement of the extremities, clenching of the jaws, and biting of the tongue. There is transient loss of consciousness and falling to the floor. These violent and sudden seizures often cause injury to the head, the tongue, and sometimes to the extremities. Protective helmets are frequently provided to those children with seizure disorders.

E. Injury to Peripheral Nerves

The possibility of injuring peripheral nerves in the extremities has been of concern to the therapist. The ulnar nerve at the elbowm the median nerve at the wrist, the common peroneal nerve at the knee and the posterior tibial nerve at the ankle are frequently cited as possible locations for injury from repetitive trauma. A survey by our own study by Takabe and Basmajian[3], however, revealed no higher risk of injury than the general population.

II. Protective Aids

A. Protection of the Head

The protective helmets are generally light weight, covered by a hard shell and a soft liner to absorb impact. Soft helmets made of foam are available for toddlers. Custom-made molded helmets are also available for better cosmetic appearance. The protective helmets are worn by children who have

impaired balance in standing and ambulation. Children with imperfect ambulatory skills or children with seizure disorders may also use protective helmets. The protective helmet can provided reasonably good protection for mild to moderate impact to the head during a fall.

B. Body Restraints and Supports

These are used to secure the child in bed or the wheelchair, preventing him from falling or from violent behavior. A belt is used when only slight support is needed. A vest or jacket can be used for more secure restraining and support. These are made of durable fabrics or nylon difficult to tear but not harmful or painful to the user.

C. Limb Support and Protection

There are various devices to hold the limbs in desirable positions. Knee separators keep spastic legs in abducted position. Slings are used to immobilize the arm in comfortably supported position. Splints are used to rest the joints of the extremities in protected position. For children who use their hands to injure themselves by hitting, scratching, picking or pulling, limb holders are used to restrict the movement of the limb. The holders are often lined with soft synthetic pile, foam, flannel or felt, so they would not cause constriction to the circulatory flow or compression to the nerves. If the restriction of movement needs to be applied to the fingers only, then a padded mitten can be used to protect the fingers from being abused.

D. Skin Protection

Numerous designs are available to protect the skin from excessive compression for any prolonged period of time. Some are designed to contour the area of compression and dissipate the pressure to a wider area of distribution. Air, water, silicon gel and a variety of synthetic foams are used in the construction of cushions and pads to achieve the task.

The elbows and heels are frequently injured from constant friction in children with impaired mobility. The protection can easily be provided by pile-lined protectors or a floatation pad which contains moldable silicone gel in the foam padding. Knees are padded for children who crawl. Poorly fitted shoes may cause ulcers in the feet. The feet must be protected by shoes of appropriate prescription.

III. Summary

Injuries to the head, limbs and skin are rather common in children with developmental disabilities. Half of all serious injuries requiring hospitalization are due to head injury. The mechanism of injuries and the prophylactic protective aids are reviewed and discussed. An ounce of prevention is worth more than a pound of treatment because of potential damaging effect of the injury.

Footnotes and Bibliography

[1]P. P. Rickham, "Accident in Childhood," Arch. Dis. of Childhood, 37 (1962), 209-213.

[2]E. B. Henrick, D. C. F. Harwood-Hash and A. R. Hudson, "Head Injuries in Children," Clinical Neurosurgery 43 (1963), 46-65.

[3]K. Takabe and J. V. Basmajian, "Motor and Sensory Nerve Conduction Velocities in Cerebral Palsy," Arch. Physical Medicine and Rehabilitation 57 (1976), 158-160.

Frank, J., Mallik, K., Chiu, W. S. and Lowry, C. P. "A Resource Guide to Protective Aids." Job Development Lab, The George Washington University, Washington, D.C., 1979.

ANTICONVULSANT ABUSE IN INSTITUTIONS

by

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I. Introduction:

It has been estimated that over 50,000 persons with epileptic seizures live in state institutions for the handicapped.[1] Most of those individuals are institutionalized for problems that include but are not limited to their seizures. Such problems typically result from severe congenital or birth defects: cerebral palsy, severe mental subnormality, behavioral disturbances and multiple physical handicaps. Epileptic seizures, however, are the source of great difficulties in the management of these individuals, with far-reaching physical and psychological repercussions. Multiple injuries as a result of uncontrolled fits are an example of direct physical sequelae. More subtle psychological repercussions can be found in the resentment and negative attitudes often generated in the staff caring for those with uncontrolled seizures.

More than any of the multiple handicaps of brain damage, seizures are at least potentially amenable to direct intervention through the use of medication. Add that to the seizure-related difficulties mentioned above and you get a clear-cut reason for the drive to control the seizures at any cost. Our study of a population of epileptics in a regional state institution was part of a larger project undertaken by the President's Commission For The Control Of Epilepsy And Its Consequences and funded by the Department of Health, Education and Welfare, Social and Rehabilitation Service, Region III. The following results are those of our own survey and study, but the conclusions have a more widespread significance for other institutionalized populations as witness the reports from other studies under the same project.

II. The Study:

A. Goals:

1. To improve seizure control in institutionalized epileptic persons.
2. To identify those individuals who do not need to be on their anticonvulsant medication.
3. To identify causes of non-compliance with therapeutically indicated regimens.
4. To coordinate our efforts with those of the Epilepsy Foundation of America which was carrying out a program of psychosocial

rehabilitation following de-institutionalization.

5. To find the most efficient or feasible means of extending any positive results beyond the period of the study.

B. The Institution:

In 1975 the total number of residents was 1150, most of whom were severely handicapped and for whom no other channels were at the time open. The medical staff of five physicians and a small number of full-time trained nurses was clearly inadequate for the load of residents, some of whom were quite ill. Seizure documentation was haphazard and, even when sought, not very reliable. The best one could hope for was a very rough estimate of the frequency of seizures for any particular individual.

C. Subjects:

The epileptic subjects were discovered by a screening of the pharmacy records, as medical records were not yet centralized or brought up to modern standards. 250 persons were listed as taking anticonvulsant medication (22% of the total population).

It became evident very early that attention should be directed at those residents identified by the counselors or the medical staff as seizure problems. These were the people who formed the majority of our population. For each individual the records were reviewed in detail. Notes were made of the initial diagnosis, any record of observed seizures, reports of EEGs and serum anticonvulsant levels. The patients were then interviewed and assessed, with particular emphasis on any signs of drug effect or toxicity. These include: drowsiness, nystagmus (saccadic movements of the eyes), ataxia (poor balance and coordination), dysarthria (slurred speech) and physical changes such as increase in facial or body hair, and hypertrophy of the gums.

An idea of the seizure frequency was obtained using two complementary methods:

a) a simple, standardized form for reporting seizures, which was already available, was used as much as possible;
b) direct communication with the staff and counselors who best knew the patient.

Despite our attempts, it was not possible to obtain reliable data for the purpose of quantifying the changes in seizure frequency. At best, estimates were gathered of major changes, such as a dramatic decrease in number of major spells or number of hospitalizations. However, as the patients were reassessed at intervals, it was possible to formulate a better picture of the mental changes and signs of toxicity as the medications were adjusted.

Serum anticonvulsant levels: From review of the residents' records, it was suspected that the serum anticonvulsant levels were not reliable. This was confirmed by running a few samples both through the institution's channels simultaneously with those obtained by us. Our samples were

tested at George Washington University using an enzymatic method (EMIT analyzer) with frequent checks by gas liquid chromatography.

A total number of 43 patients were followed in the clinic and were sufficiently evaluated to form a reasonable idea of their seizure control. Some had at least two serum anticonvulsant level examinations.

Sex: 29 male and 14 female patients.

Ages: 11-57 years with a median of 23 and a mean of 30.2 years. The diagnosis as recorded in the charts was overwhelmingly "mental retardation due to congenital or perinatal factors."

Seizure Classification: Because of limited description and unreliable observation, seizures are here divided into major motor, minor and mixed. Major motor include the generalized seizures, with or without focal or psychomotor components, the minor those unassociated with falling.

There were 24 with major, 4 with minor and 9 with mixed type seizures.

D. Results:

Of the 43 patients, it was possible to bring 7 under complete or almost complete control. Of these 3 had one or more spells per week and the others less frequent seizures. Two more patients had their seizure frequency significantly improved.

It was possible to discontinue all anticonvulsants on 5 individuals, and one among several anticonvulsants on 2 more.

One patient was brought under complete control simply by discontinuing Thorazine, a known potentiator of paroxysmal electrical activity. One patient with tardive dyskinesia was taken off the Haldol and showed regression of her symptoms.

At least two patients showed improvement of sensorium on tapering toxic doses of the anticonvulsants. (The small number of patients in this category relative to the large number with toxic levels reflects in part the reluctance of the physicians to taper anticonvulsants on patients with poor seizure control.)

Incidental diagnoses were made on 4 patients: tardive dyskinesia, Cushing's syndrome, neurofibromatosis and tuberose sclerosis.

Blood levels: 39 levels (24 Phenobarbital (PB) and 15 Dilantin (DPH) were checked by us on 25 patients and 8 (recorded in 75-6) were tested at D.C.G.H. (one at Hopkins). We include in the analysis only levels obtained by our lab, although several of the others were in the toxic range. Out of 24 PB levels measured, 20 were clearly in the toxic range (greater than 25µg/ml) with 41% above 50µg/ml. Out of 15 DPH levels measured, only 4 were over 20µg/ml, the highest being 30.2 (Table 1).

Table 1

PB>25µg/ml		DPH>20µg/ml
74.4	36.8	26.0
42.2	73.8	30.2
32.2	42.2	21.2
31.8	85.6	25.3
32.2	78.3	
49.4	76.1	
58.1	41.7	
56.4	38	
76.2	71	
40.3	43.7	
20 out of 24 levels checked were in the toxic range, between 31.8 and 85.6 (91% toxic) (41% above 50µg/ml)		4 out of 15 levels checked were in the toxic range, between 21.2 and 30.2 (26.6%)

Most patients were examined specifically for signs of toxicity. In table 2 are recorded the findings on 13 patients with a PB level greater than 40µg/ml. It is remarkable that only one patient had definite and one probable ataxia. One had definite and another possible nystagmus (out of 9 checked specifically for it). However, 6/10 were clearly lethargic and one questionably so (Table 2).

Table 2

	PB level	Ataxia	Nystagmus	Drowsiness
D.B.	74.7	neg.	neg.	pos.
P.C.	(79.1)	(-)	(-)	(-)
R.F.	49.4	(-)	(±)	(-)
E.J.	56.4	(-)		
T.J.	76.2	(-)	(-)	
T.L.	40.3	(-)	(-)	(+)
R.O.	73.8	(+)		(+)
A.P.	42.2	(±)	(+)	(+)
M.P.	85.6	(-)	(-)	(-)
K.P.	78.3	(-)	(-)	(±)
J.S.	41.7	(-)		
L.W.	71	(-)	(-)	(+)
J.W.	43.7	(-)		(+)

The conclusions we draw from these figures are that:

1. Most epileptic patients on anticonvulsants, in this institution, are likely to be overmedicated.

2. Clinical signs of toxicity (ataxia, nystagmus) are likely to be absent. Lethargy is difficult to ascertain in a population where the basic level of alertness is variable and where slowness of reaction may be a symptom of the underlying pathology.

The most probable explanation for these findings is the fact that several physicians are involved in following any one patient when he or she is admitted to the hospital because of seizures. The reflex action seems to be to increase the dosage of anticonvulsant medication, phenobarb in particular. This inevitably leads to accumulation and overdosage which builds up gradually throughout the months or years that the patient is on the medication. There is little question in my mind that such overdosed trainees are not in the optimal frame of mind to function or learn to the best of their ability.

Suggestions for Continuation of the Program:

1. Unification of epileptic care under one coordinator seems to be a must. A regular seizure clinic could be established for that purpose, where the epileptic individuals can be followed at regular intervals.

2. The clinic can be run efficiently by a staff nurse from the institution. She will know the trainees and will be available for any medical or management problems that may arise. A consultant neurologist will be available for back-up and for sharing the clinic responsibility.

3. It would be the duty of the responsible nurse in question to make sure that seizures are adequately described and recorded. She will gather the necessary data in a centralized register at the clinic.

4. Small group sessions for continuing education and presentation of audiovisual material on seizures, as well as for discussion of problems met with at the level of the cottages will be held by the nurse and other involved persons (physician, EEG technician, etc.).

5. Blood levels and EEG interpretation can thus be monitored by the consultant, providing a continuity of care not obtainable at this time.

6. Once in a running state, such a clinic can be the basis for trial of newer anticonvulsants.

In addition, it could eventually come to serve as a neurology clinic where neurologic disorders other than seizures are rescreened as necessary, bringing the diagnostic work-up of years past to the "state of the art."

Footnotes

[1]R. L. Masland, "Medical Care in Institutions," 1 April 1977, Workshop, Alexandria, Virginia.

COMMUNICATION AIDS & SYSTEMS CLINIC

by

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Introduction

For some people, speech alone is not an effective and functional means of communication. Neuromuscular disorders, brain injury, severe cognitive deficits or emotional/behavior disorders can contribute to a person's inability to produce intelligible speech. Augmentative communication should be explored as a possible avenue for enhancing the individuals present limited skills within the total interaction process.

A variety of techniques and communication aids have been developed to augment whatever vocal skills the individual demonstrates. However, the recent increase in the number of commercially available communication aids makes the process of selecting the most effective system for a particular individual more complex. Since the aid is just a tool to facilitate interaction, it must fit the entire system of communication for that individual. Interaction strategies using this tool must also be developed.

The Communication Aids & Systems Clinic, which is part of the Center for Communicative Disorders, U.W. Hospital Health Sciences Center, Madison, Wisconsin was created specifically to deal with the process of developing appropriate augmentative systems for individuals; systems which often include a communication board or aid.

The clinic team, which includes communication specialists, a positioning/seating specialist, and a communication aid specialist, works together with the client, family and community support people in evaluating the individual's needs and abilities to determine the most appropriate approach to follow.

Clinic Procedures

The following procedures have been developed as part of the evaluation process at Communication Aids & Systems Clinic.

Referral: Any person who does not use speech as a primary interaction mode may be referred for an evaluation. A referral may be made by anyone. (When hearing impairment or deafness without motor disability are a primary cause of the communication problem, there are more appropriate resources available.)

Screening: Prior to scheduling an appointment preliminary information is obtained through written reports and telephone conversations to ensure that this clinic is the most appropriate resource.

Case Review: When the appointment is scheduled additional information, medical reports, therapy and school reports and a videotape are requested. This information is reviewed at least 1 week prior to the appointment. Additional information or specially constructed equipment may be needed for the appointment. In some cases hospitalization or special transportation must be arranged.

Evaluation: The evaluation will vary in length depending on the individual problems to be tackled. They average 4 to 6 hours. In some instances the evaluation is divided between two consecutive days but often is conducted in one day.

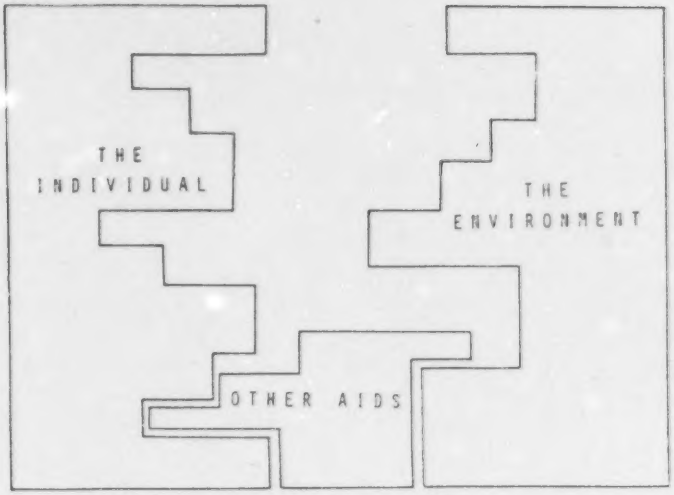
Three areas of emphasis are: 1) positioning and seating 2) communication skills and needs 3) communication aids and interfaces. Generally the evaluation begins with positioning and seating because of its pivotal role in facilitating movement which will be needed for the subsequent sections. While individual specialty evaluations are undertaken, the major part of the evaluation is done using a team problem - solving approach. Recommendations are discussed with the referred person and his/her family at the end of the evaluation and a schedule for implementation developed together.

Implementation: Depending on the recommendations made for the individual, equipment may have to be ordered and/or constructed as part of the total augmentative communication/interaction system. Subsequent visits are scheduled for adjustments to equipment to ensure proper fit. Special instructions in the care and use of the equipment are provided to the individual, the family and community members involved in his/her care or daily activities. Some recommendations involving training in the use of special graphic systems, the development of physical skills, or specific communication interaction strategies may need to be implemented cooperatively with professionals in the home community.

Follow-up: Individuals fitted with augmentative communication systems are seen for regular follow-up after the initial visit. Since the person's communication needs will change over time, as will his/her physical size and physical abilities, follow-through evaluations assess fit and function of all aspects of the system developed.

III. The Evaluation Process

The process of selecting a communication system for an individual can be viewed as a puzzle with three primary pieces. (Figure 1) Each individual brings to the evaluation their own unique physical and mental abilities as well as their past experiences and future goals. All of these factors help determine the shape of the puzzle pieces. The other major component in the puzzle is the environment in which they live. This includes the people with whom they interact as well as the physical situation in which they are operating. For example, one person might be living in a nursing home and another may be living at home and going to school daily. Those



(Figure 1) The Communication Puzzle

two situations put different constraints on a communication system for each individual. The people that the person has an opportunity to interact with will also have an impact on the most appropriate communication system. The third factor which has bearing on the actual system selected is the other assistive devices that that individual may use daily. (For example, crutches, wheelchairs, a head support system, straps, wrist splints or reaching devices.) Remaining in the middle is a gap into which must be fit a means for effectively and systematically communicating. Often it is not a case of simply one particular device being appropriate, but a variety of approaches being needed to meet the varying communication needs of the person. (For example, a child may use a pointer to indicate items on a communication board, use gestures to convey other ideas and vocalize for yes and no and to gain attention.) These are all part of his/her communication system. The critical variables to consider in examining the options available for this last piece of the puzzle, the communication system are 1) the means of indication and 2) the symbol to be used. Additional factors come into play at a later point once these two set central issues have been determined.

These puzzle pieces are all needed for communication. When the best fitting central piece ie) communication board or aid has been chosen and put in place, it is like the completion of a bridge. Now communication can flow back and forth over this bridge AS LONG AS people know the rules for crossing over. The aid is simply a tool or an enabler but people on both sides must learn how to use it effectively. Once the mechanics of operating the aid have been resolved the ways in which it can be incorporated into daily interaction must be stressed. Encouragement of further language development and increased expressive skills is necessary.

IV. Interaction Using Communication Aids

A study by Harris (1978) documents why the process must not end with selection of the aids. She studied 5 children's use of their electronic communication aids in 3 situations at school: Free play, individualized instruction, and small group discussion. In analyzing 1) the extent of participation in communication events, 2) communication modes utilized and 3) communicative functions expressed by the children she found that the children generally appeared to be passive participants, responding to questions rather than initiating interactions. They expressed a limited number of functions and tended to rely on ambiguious modes of interaction such as gestures and vocalizations. Most interaction was between teacher and child. Communication with peers occurred infrequently.

Her results suggest that message receivers tend to assume responsibility for the conversation. Clinical experience supports this finding. It appears that message receivers need to become more aware of their role in the interaction process. Specific strategies for using communication aids could include the importance of 1) asking the aid user open-ended questions and less yes/no questions and 2) encouraging the message sender to clarify comments rather than interpreting them for him/her.

Interaction using a communication aid, is different from face-to-face oral verbal conversations on a number of planes. In addition to a different mode of interaction, the speed, balance of interchange and other dynamics also change. In developing strategies for encouraging interaction and language development through an augmentative system assumptions have been based upon oral-verbal interaction. It may be more appropriate to develop a new set of assumptions based upon the constraints of the augmentative system

In the meantime the interaction process which develops using an augmentative system must be encouraged through specific strategies relevant to the individual needs and those of the other participants in the communication environment.

Reference

Harris, Deberah. Descriptive Analysis of Communicative Interaction Processes Involving Non Vocal Severely Physically Handicapped Children. Ph.D. Dissertation, University of Wisconsin, Madison, 1978.

Selected Bibliography

Nugent, C.L. Rehabilitative Speech & Language Pathology and Non-oral Communication Resources. Everest & Jennings, 1803 Pontrius Avenue, Los Angeles, California 90025.

R. Shiefelbush, (Ed.) Non-Speech Language Intervention Process. Baltimore: University Park Press 1978.

R. Shiefelbush, (Ed.) Non-Speech Language Intervention Strategies. Baltimore: University Park Press (in press).

Silverman, F.H. Communication for the Speechless. Prentice-Hall, Inc., Englewood Cliffs, New Jersey 07632

Vanderheiden, G.C. and Harris-Vanderheiden, D. Communication techniques and Aids for the Nonvocal Severely Handicapped, In L.L. Lloyd (Ed.) Communication Assessment and Intervention Strategies Baltimore: University Park Pres 1978.

Vanderheiden, G.. (Ed). Non-Vocal Communication Resource Book Baltimore: University Park Press 1978.

Von Burns, C. and Shaver, H.C. Communication Boards: Help for the Child unable to talk. The Exceptional Parent, April, 1978

16.

BIOFEEDBACK FOR HEAD CONTROL

by

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I. INTRODUCTION

A child with cerebral palsy may be able to maintain a precarious static sitting balance, however, movement of the arms and hands can disturb this balance. Conversely, movement of the head is frequently associated with abnormal upper extremity displacement, interfering with hand function. Both manifestations are serious postural problems for a child in play, educational, or later vocational settings. It has been particularly difficult to establish exercise programs specifically for neck and trunk stability. Very young children do not have the language abilities to respond to direct commands and have extremely short attention spans for repeated activities. Older children are primarily concerned with what they see as more functional activities involving the hands or legs.

Within the past eight years attempts have been made to apply the concepts of biofeedback[1] to the cerebral palsied child in order to improve sensorimotor control of the head and extremities. Sensory feedback, or biofeedback is a response oriented technique through which additional objective performance information related to the motor task is provided to allow comparison of the actual performance with the intended performance.[2] The performance information can be presented via the visual, auditory or tactile sensory pathways. Measuring and monitoring systems have been designed to provide immediate, consistent and continual feedback information related to the performance. In most systems the auditory pathway has been chosen to carry the performance information in the form of non-verbal cues such as clicks, buzzes, or tones. When working with children other techniques have been added to the auditory feedback such as the provision for a television or toy train to operate when the child is performing in the desired manner. Such response contingent activities are used to encourage continued practice.

Over a period of four years, I was the co-ordinator of a project team that worked with two small groups of cerebral palsied children for the purpose of developing and evaluating a device to monitor and feedback information related to head position. The original intent of this project was to determine if the use of auditory feedback cues and response contingent devices could enhance the ability of the pre-school aged cerebral palsied child to maintain an increasingly upright posture of the head and, if so, would the ability be retained when the feedback signal was with-

drawn after a period of training. The publication of two reports by other investigators [3,4] during the course of the project, plus our own initial results were the stimuli to change the focus of the study. We decided to eliminate the use of response contingent devices and to concentrate on the ability of the school aged child to self-monitor while in the classroom using only an auditory signal as performance information.

Requirements for selection into the two studies were similar: quadriparetic cerebral palsy; observable lack of head control in the sitting position and during arm movement; and ability to see visual stimuli and hear the auditory feedback signal.

II. PRE-SCHOOL AGED CHILDREN

Five children participated in several training programs varying in length from four to twelve weeks. The children ranged in age from 2 years 8 months to 5 years 9 months. None were ambulatory and only one was close to creeping.

A Head Position Monitor (HPM) was designed to measure the deviation of the head from the gravitational vertical and to provide an auditory signal when the head movement exceeded a pre-determined angular threshold in any direction. The transducer was mounted on a lightweight polyethylene helmet designed to conform to the head and to hold the sensor and earphones for the auditory feedback which was presented through hearing aid devices which were attached to the helmet, but not inserted in the auditory canal. A cable attached the helmet to a control unit where performance monitoring was recorded. Performance was measured by comparing the time spent in the desired angular zone with the total time of each session. Since the length of each session was not standard, real time was converted to a percentage and expressed as "percent time in zone" in order to allow for intra-subject comparisons over many days. Each subject was evaluated independently and group statistics were not used [5]. Initially the auditory feedback was a proportional sound. This sound started when the head deviated further than the pre-set angular threshold and then increased in frequency as further deviation occurred. This type of auditory feedback was found to be undesirable as it encouraged some children to maintain the head outside the desired angular zone and to make small oscillatory movements to hear the sound change. In addition, the children very quickly became bored with turning the sound off, so provision was made to add in the response contingency activities to encourage continued practice of upright head posture. Electrically operated devices such as a television, and toy train were adapted to operate from the angular threshold and feedback circuit. These devices operated when the child was performing within the designated threshold area. Later, the audio feedback was changed and a single continuous tone was provided when the child was in error. Response to the auditory feedback did not appear to improve following this change.

Children were considered successful if they made repeated attempts to operate the response contingency devices and if they could progress to using a feedback threshold closer to the vertical. Three of the five children responded to the auditory feedback consistently following demon-

stration and verbal instruction, and improved performances when using the response contingency systems. These children had individual training programs designed to maximize each child's abilities and interests. Two of the children demonstrated no consistent response to either the auditory or the response contingency feedback, and spent long periods of time and even entire trials without initiating movements. Repeated passive and active assisted movements with verbal instruction and encouragement did not result in consistent independent attempts by these two children.

All children commenced therapy with the angular threshold set at 50 degrees. Successful children all progressed to using a 30° threshold and one child could operate the television at the 20° threshold and maintain a performance in excess of 80 percent time in zone. The consistent attempts to use the response contingent devices were most remarkable. Two distinct types of action were noted. When using the television, stability was essential to insure the continuity of the program being watched. On the other hand, the action that makes the train attractive is the ability to have it stop and start. Games were devised so that motor planning was required of the child to stop the train at selected points and then start it moving again. Subsequent efforts to link the auditory feedback to the toys and then withdraw the toys and put the child in the classroom using the auditory cue remained unsuccessful with this age group.

III. SCHOOL AGED CHILDREN

Five children were selected to participate in a self-monitoring auditory feedback program. The feedback signal for this group was an oscillating tone, similar to that of an emergency vehicle. The auditory feedback was heard when the head exceeded the pre-set angular threshold. No response contingency devices were utilized in this program. All children were female, and ranged in age from 7 years 1 month to 11 years 5 months. Gross motor ability was limited to skills at the 3 to 9 month levels. Two children were verbal and three communicated by non-verbal means.

The problem of where to set the feedback threshold was more difficult for this group of children. We wanted to generate a stable upright head position for attending to chalkboard teaching, but we had to allow for "head down" activities involving desk work. From previous investigation with normal children,[6] we knew that 25° was the minimum angle we could demand for desk work[6]. Following assessment it was determined that four children should practice at 25° angular thresholds and one child at a 35° threshold. Children were taught how to use the feedback in 3 to 7 individual training sessions. They then started to pracice in the classroom. (Figure 1) Classroom feedback sessions lasted from 5 to 64 minutes dependent upon the chil's ability to maintain the head within the required threshold under feedback conditions. Increases of 24 to 62 percent were seen for the 5 children. These high performance rates were not maintained when the feedback was removed after nine weeks of practice.

Three children demonstrated consistent self-monitoring ability and were able to work independently for a minimum of 25 minutes at a time while retaining performance levels in excess of 80 percent time in zone. The children who achieved this level all had enough hand skills to either use

a pencil grossly or use a typewriter, and were able to work independently on classwork. Two of these children were verbal and one was non-verbal.

Figure 1. Head Position Monitor

The two children unsuccessful at self-monitoring had no independent method of communication, could not operated any learning systems equipment and always worked with an aide either individually or in a group. Responses to classwork were given by eye signals. These two children rarely responded to the audio feedback for more than 15 to 20 minutes, even after nine weeks and continued to need verbal encouragement at times to respond. Their performances were extremely variable. It is possible that the lack of persistent response was related to behavioral factors in addition to the somewhat poorer motor skills. These two children had little experience of working on a task independently and successfully, and had not developed independent work habits.

IV. SUMMARY

The long term aspects of physical and mental fatigue were not directly addressed in these investigations. It should be recognized that the presentation of the feedback required the child to divide the attention and to increase the level of awareness to attend to the postural system as well as ongoing activity. These studies certainly illustrate that correction is possible volitionally, and that when provided with appropriate performance information children will temporarily make great efforts to improve performance. The drop in performance when the auditory feedback was removed indicated to us that postural awareness had not progressed to an automatic state. The ability to maintain an erect and stable head position did not appear to be important to the children. If this is so, it is unlikely that they would have continued to practice independently. Further exploration should emphasize improved functional applications.

ACKNOWLEDGEMENTS

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References

1. Basmajian, John V. (Ed) Biofeedback - Principles and Practice for Clinicians Baltimore: The Williams and Wilkins Company, 1979.

2. Herman, Richard M. "Augmented Sensory Feedback in the Control of Limb Movement" Neural Organization and its Relevance to Prosthetics Ed: W.S. Fields, New York: Intercontinental Medical Book Corp. 1973, pp. 197-215.

3. Harris, F.A., Spelman, F.A., Hyner, J.W. "Electronic sensory aids as treatment for cerebral palsied children" Physical Therapy 54 (1974) 354-365.

4. Wooldridge, C.P., Russell, G. "Head position training with the cerebral palsied child: An application of biofeedback techniques" Archives of Physical Medicine and Rehabilitation 57 (1976) 407-414.

5. Martin, J.E, Epstein, L.H. "Evaluating treatment effectiveness in cerebral palsy. Physical Therapy 56 (1976) 285-294.

6. Leiper, C., Lang, J., Herman, R., Miller, A., Meddock, T. "Augmented Sensory Feedback of Head Position Studies with Children Having Cerebral Palsy - Final Report. Rehabilitation Engineering Center, Moss Rehabilitation Hospital, Philadelphia, 1979.